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THE SELF HELP WAY

mutual aid and health

Jean-Marie Romeder
and contributors

Canadian Council on Social Development

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The Self-Help Way

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Mutual Aid and Health

Jean-Marie Romeder
with contributions from
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Andrew Farquharson
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Canadian Council on Social Development
Ottawa/Montreal

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To Lindy Fraser and Len Borman,
mentors and friends of the
North American self-help movement

Table of Contents

Foreword xi

Preface xiii

Acknowledgements xvii

Chapter 1: Introduction 1

The Resurgence of Self-Help 1
My Discovery of Self-Help 4

Chapter 2: Three Case Histories of Self-Help Groups 9

Lindy and OSTOP: Good-bye Crutches! 9
Christian L.: The Drunk Who Beat the Bottle 14
Ann X and Mary Y: Coping with Mental Illness 17

Chapter 3: The Characteristics of Self-Help/Mutual Aid 23

Mutual Aid in Self-Help Groups 23
Suffering: What Triggers Self-Help/Mutual Aid 26
The Three Characteristics of Self-Help/Mutual Aid 27
—Common Experience and Resonance 28
—Self-Help is Essentially Free 29
—Equality 30
The Helper-Helpee 32
A Definition of Self-Help Groups 32

Chapter 4: Motivation and Dynamics of Self-Help 35

Features of Personal Mutual Aid 36
—Symmetrical and Asymmetrical Mutual Aid 36
—Mutual Aid and Autonomy 37
—The Magic of Self-Help 38
Human Motivation and Personal Mutual Aid 39
—Basic Human Needs 39
—Motivation in Self-Help/Mutual Aid 41
The Dynamics of Self-Help 43

Chapter 5: Personal Health 49

The Concept of Health 49
Person-Centred Health Promotion Model 52
—The Person: Self-Care 54
—Others: Help and Mutual Aid 55
—Professionals: Help and Care 55
—Information: Learning and Relearning 56
—The Environment: Collective Action 57
Personal Health and Self-Help Groups 58

Chapter 6: Seeking Help and Joining a Self-Help Group 63

Help or Mutual Aid: The Choices Available 63
The Myth of Autonomy 65
—Weakness 66
—Uselessness 66
—Indebtedness 66
—Social Courage 67
The Art of Asking for Help 68
—Accepting Unavailability 68
—Recognizing our Need for Help in Time 69
Joining a Self-Help Group 69
Equality, Humility and Anonymity 71

Chapter 7: Evaluating Self-Help Groups (F. Lavoie) 75

What Happens in a Self-Help Group? 76
—Activities 77
—Helping Factors 79
—Ideologies 86
How Effective are Self-Help Groups? 87
—Impact on Members 88
—Organizational Effectiveness 90
Conclusion 91

Chapter 8: The Self-Help Movement in North America (H. Balthazar) 97

The First Canadian National Meeting 98
Self-Help at Work 99
Later Film-making 101
The 1984 International Self-Help Conference 102
Curriculum Development for Professional Schools 104
Self-Help Clearinghouses 104
— U.S. Developments 105
— Canadian Developments 107

Chapter 9: Self-Helpers and Professionals (A. Farquharson) 113

The Unique Contributions We Both Bring 114
The Role of Self-Helpers 117
Some Thoughts on the Care, Feeding and Use of Professionals 119

Chapter 10: Conclusion 125

Risks and Limitations 127
Social Perspective 129
The Future of Self-Help Groups 131

Epilogue 135

Foreword

Throughout my years as a medical practitioner, and through first-hand experience, I have come to appreciate the value of self-help and mutual aid for coping with health problems and crises. The sharing of common experiences through mutual help groups, particularly if there has been great hurt or suffering, unleashes something very special in the way of healing, as people who have known its effects will attest. Society in general, and human services personnel in particular, have much to learn about what can be accomplished through self-help/mutual aid. Today, the self-help movement is burgeoning and its growth gives promise for the day when the self-help way will be accorded the respect it deserves as one of many established helping methods. In the meantime, every effort must be made to support and nourish the development of a genuine partnership between the health, social services, and self-help communities. In the end, it will mean that all who seek help in society will be better served.

To self-helpers, there is still serious work to be done to get professional associations in the human services to recognize self-help as an important element in the range of helping methods. Many professionals still believe that self-help is nothing more than the blind leading the blind. To them, transformation, change, and healing are the prerogative of an elite who possess knowledge and techniques bestowed by specialized training institutions. It is difficult for these professionals to realize that the blind can indeed lead the blind. Not surprisingly, in a society that places so much emphasis on structured training, professionals all too often relegate the benefits of shared experience to a position of relative insignificance, without sufficiently recognizing the major role it plays in human behaviour and motivation.

But there is reason to be hopeful; many professionals have "crossed the Rubicon," as it were. Some have played key roles by helping to found major self-help groups. Others have learned that very special skill of being able to help groups who want help, while respecting the group's evolution and autonomy. Vanguard teaching

professionals have introduced the study of self-help into professional training schools through behavioural science or other courses. There are also professional researchers and writers on the subject who genuinely understand self-help and whose activities have advanced the self-help movement.

There are also important economic reasons why self-helpers and professionals should coordinate their efforts to help people. Society is changing at a very rapid rate, creating havoc in the lives of many. There is an increasing demand for services, yet budgets and human resources are not expected to be able to meet all of these new demands. But with dialogue and mutual understanding about how people in need can best be served, those who need help will not fall by the wayside. Professionals who understand self-help can properly refer people to self-help groups, and self-helpers who understand when professional guidance is needed can suggest it to their group members, so that people get the help that is most appropriate for them. A partnership between traditional professional care and the self-help movement can provide a superior service.

For the general public, to whom this work is also addressed, this book can serve as a map, a primer introducing the many facets of self-help. Not enough has been written on this subject for general consumption. It is an excellent means of reaching those for whom the written word is the preferred medium.

This book touches on many issues of central importance to the promotion of self-help. Its appeal to the general public and to professionals makes it an important addition to the general fund of self-help resources. I am particularly pleased that a network between Canadian and American self-help clearinghouses has been established. There are mutual benefits in such arrangements that are sure to strengthen the self-help communities in both countries. This may, in turn, lead to more formalised links with self-help organizations in other countries, a step that would add an international dimension to the whole field of self-help/mutual aid.

C. Everett Koop, MD, ScD

Preface

This short book on self-help groups was written for the general public. It is intended primarily for people who are thinking of joining a self-help group because they are facing serious difficulties or because someone close to them is in that situation. The book is also for people who already belong to self-help groups, or who are close to someone who is a member.

The work is intended for a third audience as well — professionals in health and social services who know little about self-help groups but who want to increase their knowledge, if only to be able to refer some of their clients to appropriate groups. Most of these professionals (or students) work in disciplines such as social work, nursing, medicine, psychology, psychiatry and physiotherapy.

Readers will discover the general underlying principles on which mutual aid and self-help groups operate, the role of mutual aid in personal health, the diversity of groups, and the importance of the self-help movement in North America. At the same time, readers will be introduced to some more general or theoretical considerations in chapters 4, 5 and 7.

This book offers a summary of current knowledge in the field of self-help/mutual aid, expressed in the most straightforward manner possible and inspired by my own observations of self-help groups and the writings of numerous authors and researchers. To describe the nature of self-help groups, I have presented a minimum number of concepts and have tried to be clear and concise.

Thus, in Chapter 3, after focusing on three key characteristics of mutual aid, a new definition for self-help groups is proposed. Chapter 4 outlines a theory of motivation for mutual aid that gives readers a better understanding of the forces and dynamics at work in the mutual aid practised in self-help groups. In Chapter 5, my concern with establishing mutual aid as an option to which a person with health problems can turn led me to propose a model of personal health.

When health is discussed in this book, it is in no way limited to a notion of individual health focused purely on the physical

aspects of health. In fact, self-help groups are generally more concerned with psychological distress than the physical pain associated with a crisis or chronic health disorder. Thus, personal health encompasses psychological and social elements, including our perception of ourselves and our relationships with others and with the society in which we live.

Chapter 6 examines the sources of reluctance many people have to self-help groups and the way one can overcome them.

Chapter 7, by Francine Lavoie, provides an informative overview of numerous studies on self-help groups. It focuses on three specific aspects of self-help groups — activities, helping factors, and ideologies. It also provides a good summary of research findings on the five main helping factors.

In Chapter 8, Hector Balthazar provides an overview of the activities that have lent support to the self-help movement, a movement whose origins are in North America. As one of Canada's principal advocates in this field, he describes a number of activities undertaken by members of self-help groups and various professionals, activities which governments have now started to support. In particular, we find a good description of the different types of self-help clearinghouses that have been developed in the United States and, more recently, in Canada, as well as a description of the crucial role these clearinghouses play in sustaining the movement.

In Chapter 9, Andy Farquharson presents his observations on the similarities and differences between the activities of members of self-help groups and those of professionals. He offers suggestions to self-helpers for drawing maximum benefits from the full potential of their groups while recognizing when to call upon professional help.

The limitations and risks of self-help groups are dealt with briefly in the concluding chapter, which also includes some reflections on the future of self-help groups.

Readers familiar with mutual aid, whether through friends or relatives or through their own involvement in various groups or associations, may wonder why we are paying such detailed atten-

tion to an activity that is so widespread. Everyone is involved in some form or other of mutual aid. In fact, mutual aid, as practised in self-help groups, differs somewhat from other forms of mutual aid encountered in everyday life. This is why we refer to it as self-help/mutual aid.

Self-help can mean either helping oneself *without* the assistance of others or helping oneself *with* the assistance of others. In this book, we focus on the second meaning, as it occurs in self-help groups. This explains why some have characterized the benefits of self-help groups as follows: **"In self-help, you get help, you give help, and you help yourself."**

JEAN-MARIE ROMEDER

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While the authors assume full responsibility for their respective chapters, the numerous discussions that took place among them contributed greatly to improving the overall structure and content of the book.

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1

Introduction

"You alone can do it, but you can't do it alone."
(motto of a self-help group)

The Resurgence of Self-Help

We've heard more and more about self-help groups over the past fifteen years, both in the daily press and in popular and specialized magazines. A number of authors have recently devoted entire books to the subject, presenting findings from numerous studies, particularly North American ones.[1,2]

The self-help movement has created new forms of solidarity in the past fifty years, particularly in the area of health and social services. Indeed, the entire self-help/mutual aid movement traces its roots to the founding of Alcoholics Anonymous in the United States in 1935.[3]

A directory of self-help groups in Toronto attests to their impressive numbers — about 170 groups or networks — and to their diversity.[4] They fall into about fifteen categories dealing especially with alcoholism, drug addiction, obesity, bereavement, disabilities, criminal behaviour, homosexuality, or violence. Certain groups, such as Depressed Anonymous are for the people directly affected, while others, such as Friends of Schizophrenics, are for family members. Some groups offer support for people suffering from

specific illnesses, such as asthma, anorexia and bulimia, cancer, diabetes, epilepsy, heart disease, and herpes, to name a few. Groups also exist to help people adjust after major surgery, such as open heart surgery and colostomy.

Some groups have grown into vast networks with regional or local branches to which are attached chapters that are virtually autonomous. In Toronto, the Alcoholics Anonymous (AA) network holds some 300 meetings a week, not including meetings for the families of alcoholics (Al-Anon) and for adolescents in families with an alcoholic (Alateen). A new network of groups, Adult Children of Alcoholics (ACOA), was founded more recently.

Among the major self-help networks in North America, groups for the obese like TOPS (Take Off Pounds Sensibly) and Overeaters Anonymous are noteworthy. These large networks have several branches in most large Canadian and American cities. A pilot study carried out on self-help groups in Canada in 1980 listed 107 groups in metropolitan Winnipeg and 141 in metropolitan Ottawa just for alcoholics, their families, and people suffering from obesity.[5]

A 1980 American directory lists ten organizations with more than a thousand affiliated groups each.[6] Together these ten organizations account for 50,000 groups in the United States; their combined membership totals roughly a million people.

As Powell emphasizes, however, there is no reliable global estimate of the total number of self-help groups in the United States.[7] Precise figures do not exist for Canada either. The 1980 pilot study conducted in a number of Canadian cities suggests that several hundred thousand Canadians belong to self-help groups.[8] These estimates may be rough, but they indicate that self-help groups are an important social phenomenon, both in Canada and the United States.

Self-help groups and networks have grown so vigorously during the past fifty years that we are now witnessing a real revival in the practice of mutual aid. The movement's success is attributable to the diverse ways self-help groups respond to seri-

ous individual needs, as well as to the complex set of factors that underlie our society's evolution.

Self-help groups satisfy two main types of needs. The first is the simple need for help in dealing with a crisis or with serious difficulties. People in these situations need support; they need to know they are not alone, that others have had similar experiences, and that they can share their distress with others. They also need to learn how their fellow sufferers have overcome their difficulties. They need to feel they belong — that they are part of a community, a family, a friendly group of people they can count on.

The second need is for personal independence and autonomy. This need varies considerably with culture and education. We are all born with the desire to be autonomous, to be in charge of our own lives, and this becomes more acute through contact with excessive controls and rigidities typical of large institutions, bureaucracies, and various professions. For this reason, many people are critical of the health and psycho-social services provided by government and professionals, believing that these services are inadequate, overly rigid, inhuman, expensive and impersonal.

This concurrent need for support and autonomy often surfaces in ambiguous or contradictory ways at different times in our lives. The key to the success of self-help groups lies in their ability to offer the means of satisfying both needs. Increasing one's own autonomy while learning how to accept help from others is a dialectic relationship illustrated by the motto "You alone can do it, but you can't do it alone." This motto was adopted by the Integrity groups (aimed at personal growth) founded by O.H. Mowrer in the United States.

It is natural to wonder about the birth of these self-help groups. In an excellent discussion of their characteristics and growth, Borman points out that many self-help groups that have grown into vast organizations were formed with the collaboration of professionals working in health care, social services, psychology, or the church.[9] Looking at ten large organizations founded between 1935 and 1975, Borman shows that professionals played a

key role in the founding of six and assisted the other four at various stages in their development.

Many other organizations were founded by non-professionals who had weathered a crisis or illness and recognized the benefits and support such a group could offer others in their community trying to cope with similar problems. Such groups are constantly springing up and often remain strictly local, without seeking to establish branches elsewhere.

In the following chapter, case histories relate how two such local groups were founded recently, aptly illustrating the driving forces behind the revival of the practice of mutual aid.

Inasmuch as self-help groups deal with very personal human problems, I also discuss my own introduction to the practice and benefits of mutual aid. The following pages explain, at least in part, the reasons for my interest in this phenomenon.

My Discovery of Self-Help

I first heard representatives from self-help groups talk about their organizations in 1978, at the annual meeting of the Association of Humanistic Psychology. During a workshop on social change, Frank Riessman of New York spoke about all kinds of groups whose existence I had never even suspected and who were giving moral support to people dealing with a vast array of problems. Frank's remarks sparked my interest, and I decided to study the movement after I returned to my work at the Department of National Health and Welfare in Ottawa.

Although my first contact with the world of self-help groups immediately struck a responsive chord in me, I was interested in a purely intellectual way.

Only later, after I had established personal relationships with members from various self-help groups, was my heart truly moved. In discussing this new interest with colleagues and friends, and in attending self-help meetings, I met many people whose stories convinced me of the benefits they had gained. The first meetings I went to were held by parents and friends of people with mental

illness. I then attended meetings held by Alcoholics Anonymous. I was able to see the distress of some members, but also felt a wonderful human warmth.

As I was becoming acquainted with the world of mutual aid, I was deeply moved by the 1979 Montreal self-help fair where forty groups were represented. A panel of group representatives related their own experiences and described how their group was formed and how it worked. I remember being struck by the testimonial of a *Solidarité-psychiatrie* member who spoke about his numerous hospitalizations, including a two-year stint in a psychiatric hospital. The way he expressed himself, his sense of humour, and his description of his group's activities convinced me of the value of such a group in improving the quality of life for former residents of psychiatric hospitals. At the same time, I became aware of the key role a social worker had played in getting the group started.

Another group at the Montreal fair made a stong impression on me. This was the Cancer Self Aid Group (CASA). I spent some time talking to the group leader, who was a nurse, and to a cancer patient. I learned that a member of the group had died a few weeks earlier and that fellow group members had taken turns to ensure he had company at his bedside as much as possible; several of them managed to be with him when he died. I marvelled at the group's ability to maintain such support. This group particularly impressed me because it dealt with the question of dying and its acceptance. I found it extraordinary that people could help one another make the most of the time they had left, overcoming or reducing the fears surrounding separation and death, the greatest separation of all.

These testimonials from members of various Montreal self-help groups influenced me greatly, spurring me on to try to understand the driving forces behind a movement that was still very new to me.

In the years following my discovery of the rich diversity of these groups, I tried to understand what personal mutual aid really is, and its relationship with friendship. I concluded that

friendship and mutual aid are often closely related. A personal example illustrates this point.

I established a strong mutual aid relationship several years ago with a neighbour, now one of my best friends. A year previously, my wife and I had separated after seventeen years of marriage. I learned one day that my neighbour and his wife had just separated as well. Although we had been neighbours for a few years, we hardly knew each other and our contacts had been very limited. The Christmas following my separation, my neighbour had given me a small gift and offered my children a similar one for their mother. This gesture moved me deeply, particularly as my first year of separation was very painful, marked as it was by moments of depression and, at times, deep loneliness.

When I learned, with great surprise, that my neighbour and his wife were also separating, I invited him to go out for a beer a few evenings later. That is how our relationship began. During the next two years we saw each other often. As we shared our pain, our fears, and our questions about our new lives as separated and then divorced men, we got to know each other. We spent many days together, often with our children, for birthday celebrations, picnics, and canoe outings. At the outset, my neighbour was often overwhelmed by events that I could already handle quite well, as my separation had taken place a year before his. Accordingly, I was able to be of help to him. At the same time, I noted my own progress; certain things no longer bothered me at all. It was then that I remembered a proverb an aunt had often repeated to us when I was young: "We often need someone in greater need than ourselves."

This experience showed me how the feelings we share with others during times of crisis can often lead to strong friendships. The discovery of new inner strengths in the wake of a crisis is also commonly experienced by members of self-help groups. These new strengths are the fruit of a new kind of bond within groups and they enable members to improve the quality of their lives after a setback. Some members also regain their love of life or discover the wonder of life for the first time.

As someone who is interested in all aspects of health, I can personally affirm that mutual aid, like friendship, is one of the fundamental requirements for good personal health. We will examine this assertion in the chapters that follow.

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8. See Romeder, J.-M., reference no. 5, above.

9. See Lieberman, Borman, et al., reference no. 3, above.

2

Three Case Histories of Self-Help Groups

The three case histories in this chapter will give readers concrete examples of self-help groups and help them understand some of the factors motivating people to start self-help groups or to join one. Each story reflects the specific circumstances that gave rise to it.

The first case history is taken from a group called OSTOP, which assists people suffering from osteoporosis, a bone disease that afflicts many seniors, especially women. The second case history shows the considerable support Alcoholics Anonymous gives alcoholics. The third case history relates how two women, each the mother of a mentally ill adolescent, founded a group for parents and friends of the mentally ill.

Lindy and OSTOP: Good-bye Crutches!

OSTOP is a self-help group whose members suffer from osteoporosis, a bone disease that considerably diminishes the density and solidity of the bones. This weakening of the bones causes all kinds of complications and pain, including falls, fractures of the wrist, ribs and hips, and even compression and fracture of the spine, often leaving the victim hunchbacked. Osteoporosis is a

chronic disease; it develops slowly and lasts indefinitely. Its victims are usually women over 50 or 60, though some older men are affected as well. As with many chronic illnesses, there are ways to prevent, relieve and control the disease, but not to cure it. Particular importance is placed on nutrition and specially adapted physical exercises, both for preventing osteoporosis and maintaining the health of people suffering from this illness.

Ottawa's OSTOP group meets every week. About twenty members participate in these meetings which feature shared activities, including the exchange of information and personal experiences, information sessions with the occasional speaker, and a half-hour workout done to slow music. The slow rhythm of these exercises acts as a stimulus, giving members new or renewed courage to move rusty joints and limbs. The information sessions offer educational videos, games, presentations, and discussions of magazine articles, all aimed at keeping members up to date on new advances in the understanding of the illness.

The group meets at the Good Companions Seniors' Centre, which is centrally located and well served by buses and has a cafeteria. Some group members also meet there for other kinds of friendly exchanges.

How did OSTOP come to be?

OSTOP was founded in 1981 by Lindy Fraser, who was 87 years old at that time! The story we are about to relate is truly astonishing.

Lindy was born in 1894 in Manitoba; she died early in 1989, at the age of 94. In her youth her health was good, but she began to suffer back pains that exhausted her to the point where she could not carry out some activities. By the time she was twenty, Lindy began to suffer far greater pain that sometimes robbed her of all her energy, and she began to consult doctors. In her thirties, the pain worsened. She fractured a wrist and a rib. Her spine collapsed, pinching nerves and causing almost intolerable suffering. She felt the need for medical help, but doctors were unable to find anything wrong. Lindy thought some doctors believed she was just imagining her pain. Fortunately, her husband Peter and son

Doug believed her and provided support. Thanks to them, she was able to cope with her pain and endure increasingly frequent fractures of her arms, wrists, toes and ribs.

In 1947, at the age of 53, Lindy became too disabled to continue working. It was then that a young doctor succeeded in diagnosing the illness that had plagued her for years; she had osteoporosis. It came as an overwhelming relief to Lindy to discover that all her pain and her accidents had a cause and a name! Unfortunately, there was no known treatment then, and Lindy had to wait a number of years and suffer numerous hospitalizations before benefiting from a treatment based on calcium and Vitamin D.

Lindy's condition continued to deteriorate, however, and her deformities became more and more apparent. In 1973, bedridden again and almost 80, Lindy was advised by her specialist that nothing more could be done. But this elderly woman would not accept the verdict. Her love of life was too strong. Since the calcium treatment had been very helpful, Lindy was convinced that other treatments must be possible, and she was right. A doctor suggested she try an experimental medication based on sodium fluoride and calcium.

It was then that the miracle slowly began to unfold, thanks to Lindy's determination to recover her health and to the assistance of many devoted helpers. It took her a year to regain her ability to walk unassisted; for eight months she alternated between her bed and a wheelchair, then for four months she walked using two canes. At the age of 79, Lindy learned to walk for the third time in her life, strengthened as before by the unswerving support of her husband Peter. Misfortune struck a few years later, however, when Peter was diagnosed with cancer, to which he succumbed in 1977. Lindy was widowed at the age of 83. She went through a period of profound despair before gradually overcoming the pain of her loss.

In her youth, Lindy had thought she was the only one to suffer from this nameless illness, from the crushing onslaughts that regularly overwhelmed her, demanding all her strength and the help

of family and friends. She knew now that her illness had a name — osteoporosis — and that others suffered from it too. One day after her husband had died, she thought of sharing her experiences with others. Her years of crises, setbacks, and recoveries had taught her much: how to adjust her lifestyle, find the best diet, discipline herself to exercise regularly, and find medical help to slow the deterioration of her all-too-fragile bones. All the help she had received could be shared with others who needed it; this vision gave her a new purpose in life. Lindy read everything she could find about osteoporosis, nutrition and health in general. Then, at the age of 87, Lindy began "a new career," as she put it.

In the beginning, her goal was simple; she wanted to share her experience with fellow sufferers in her city and help them regain control of their lives. Lindy understood how reluctant people with osteoporosis are to go out and meet others. She started by contacting a small community centre with the hope of obtaining a meeting space. Her story so impressed the centre's staff that they arranged for Lindy to meet a journalist from Ottawa's daily newspaper. The journalist gave Lindy's story a full-page spread and included comments from her doctor. The new group's inaugural meeting was mentioned in the article, and more than twenty people turned up for it. This meeting in October 1981 marked the birth of the first self-help group for osteoporosis sufferers, an organization that would later be named OSTOP.

At first, the meetings were held every two weeks, then, after a time, every week. At every meeting, Lindy would lie on the floor to demonstrate her basic exercises, emphasizing that daily exercise plays a vital role in stimulating the bones to absorb calcium. Lindy needed no tricks to persuade others of the possibility of regaining control of their lives. Her body, with all its deformities, bore witness to her disease.

Lindy and her OSTOP group were featured in many newspaper articles and television reports. With the help of the media she was able to spread her message, thus raising interest and eventually helping to establish similar groups in other cities in Canada and abroad. Besides attracting new members, Lindy was successful in

enlisting the support of many volunteers who did not suffer from osteoporosis to look after administrative tasks and publicity. Finally, a retired nurse recruited by Lindy and pleased to contribute to her cause, became involved in a number of activities, and eventually acted as the group's president for four years.

A second way Lindy promoted self-help for osteoporosis sufferers was by carrying on a great deal of correspondence with people suffering from the illness. In response to articles and television reports, letters would arrive from all over requesting information and advice. The self-help group's momentum increased and similar groups were started elsewhere.

Three aspects of OSTOP are noteworthy. The first is the increased autonomy that its members gained. Often, by the time they joined OSTOP, new members had lost much of their independence as a result of their disease, as well as any hope of regaining it. In the weeks and months after joining OSTOP, most of them regained a large part of their autonomy, thanks to the activities of the self-help group and Lindy's example. For her part, Lindy, who had received various forms of help and support throughout her life and whose love of life was as strong as ever, was able to maintain her own autonomy, despite the fact that it was constantly under attack from her illness. By founding OSTOP, she enabled others to regain their lost autonomy, while maintaining her own.

The second aspect is the professional and volunteer help OSTOP received. At the outset, Lindy's doctor acted as the group's medical adviser, and many health professionals participated in OSTOP's activities at various times. In addition, many volunteers stepped in to help members with the tasks necessary to run the group's meetings.

The third notable aspect of OSTOP was the establishment of a group structure which allowed Lindy to relinquish her role as group leader after several years.

Christian L.: The Drunk Who Beat the Bottle

Compared to the diminutive Lindy, Christian L., a strapping fellow in his early fifties, looks young. Christian L. is a long-time member of Alcoholics Anonymous (AA), which helped him rebuild a sober life. Christian was born into a well established and moneyed Quebec family. In 1979, after many trials, lapses and relapses into alcoholism, interspersed with a few attempts at rehabilitation, Christian hit rock bottom. He was reduced to the life of a bum, drinking all day long, living in a small basement room. The way things were going, Christian's fate seemed certain — he would either end his days as a bum or within a few months find himself confined to a psychiatric hospital.

Today Christian leads an active and dynamic life. He has not touched a drop for years, has remarried and is living happily with his new wife.

How did Christian beat alcoholism? What enabled him to regain control of his life? This is what we will discover in examining the role AA played in his life.

Christian's drinking problem worsened slowly over a number of years. At about age 28 his drinking became excessive, despite warnings from his employers, family and friends. At the start of his career Christian had been a successful professional. After several years in his home town, he was transferred to another city to take on important new responsibilities. Christian had become a father and was living in a beautiful home, thriving in his new social and professional milieu. To overcome the daily tensions in both his professional and personal life, however, Christian continued to drink, even though he recognized the consequences of his excesses. For him alcoholism was a sickness of false pride. "You drink out of a sense of bravado," he would claim.

At the urging of his wife and some of his colleagues, Christian began to attend AA meetings, and he underwent his first detoxification treatment. Although he claimed that he wanted to stop drinking, he was not truly committed to it. His first contacts with AA were sporadic and lasted several months. Christian attended

several meetings a month. A few times, he lied about attending AA meetings.

Christian's problems increased with his drinking, until finally, in his early forties, his world collapsed: loss of job, divorce... Alone, without any daily routine or support, Christian drank more heavily than ever, despite a second attempt at detoxification. By 1979, when he was 42, Christian had degenerated to the point where his life was in danger.

Several events testify to this decline. Although he had greatly admired his father, he attended his father's funeral in a drunken stupor. Later he moved in with his mother, but his all-day drinking bouts kept her from sleeping. Finally one of his brothers threw him out of his mother's house, and Christian went to live in a small basement room. One day, his eldest son summoned up enough courage to visit him, but Christian was drunk and incoherent, and did not even recognize his son.

At four o'clock one morning, Christian asked a taxi driver to take him to the liquor store. The driver drove him all over town, brought him back to his room and charged him a whopping bill.

Two key events then forced Christian to take hold of himself. He was given two ultimatums in mid-January 1980.

The first came from Christine, an old schoolfriend he met up with again. They were strongly attracted to each other, and Christine was ready to act on her feelings, but on one condition only: "Stop drinking, get treatment, or forget your future plans with me." This warning was the first Christian received.

The second ultimatum came from his doctor, who was also a friend and a member of AA: "Christian, this is my last visit, and I simply want to warn you that at the rate you're destroying yourself, in six months — and I'm serious — you'll be locked up for good."

Determined not to lose his sanity and spurred on by his love for Christine, Christian contacted the detox centre where he had previously tried to stop drinking. The centre made an exception for him and readmitted him on a trial basis. January 18, 1980 was a red-letter day for Christian, marking the beginning of a new

sobriety from which he has not strayed since. His stay at the centre lasted five weeks. Christine visited him almost every day after he made it through the first ten days of isolation. Christian designed his own program of activities, which he had to submit every day to his therapist for approval. He attended AA meetings two evenings a week on average, often accompanied by Christine. This is how Christian learned once again to become autonomous, discovering the pleasures of freedom but also its limits.

Christian believes that his progress was due above all to discovering AA, which accepted him as he was and gave him the freedom to progress at his own pace. In fact AA became a new family for Christian — a support structure that he could always trust and that enabled him to evolve without drinking.

For years Christian tried to analyze and understand his alcoholic behaviour by constantly asking "why me?" AA helped him set the question aside, stop brooding, simply accept his condition, and make progress in his rehabilitation. Through AA, Christian met people who knew how to listen and offer support and advice. He felt both understood and accepted.

For his part, Christian was able to help others and participated in the various activities and organizational tasks of AA in his city or in cities he visited. One senses that the help Christian gave other alcoholics encouraged him to persevere and pursue his own progress. Christian fondly recalls the beautiful friendship that developed between himself and Tom, whom he began to sponsor nearly four years ago. Tom was initially quite withdrawn, in terrible despair and seriously contemplating suicide. In the weeks that followed, Christian had the satisfaction of seeing Tom change and begin to take control of his life. As his sponsor, Christian was on call night and day to support Tom should a crisis arise. Christian shared his own story of alcoholism with Tom and encouraged him to attend AA meetings. At the same time, Christian introduced him to other AA members who might have things in common with him and explained the significance of the practices and rituals of the group. After several months, after Tom had listened to Christian's problems or given him advice several times, their re-

lationship changed from one of helper-helpee to one of mutual aid; it had become more symmetrical.

Christian emphasizes, however, that it is not always easy to be a sponsor. For him, self-help is first and foremost listening, but he knows that there are limits to listening. One day Christian interrupted Gilles, a group member who had been talking incessantly and repeating himself: "Gilles, you'll have to learn to stand on your own two feet." Christian believes that one has to be firm enough to let others look after themselves. "It's tricky; you have to have gone through a variety of experiences to know when to intervene, but nonetheless you recognize when it's time to be firm."

Sharing, which is a key activity in all self-help groups, is part of the ritual of AA meetings, where it takes on a structured form. Christian uses this opportunity to relate his experiences as a recovered alcoholic. He stresses the importance of the meditation he practises each morning by reading "24 Hours," a small collection of reflections and inspirational sayings used by many AA members. The book has one page for each day of the year. "Often it reminds me of my vulnerability, and my need for mutual aid to stay sober," Christian says.

Christian travels quite frequently in his new job. Almost invariably, the first thing he does upon arriving in an unfamiliar city is to call to find out when and where Alcoholics Anonymous holds its meetings. Even if he cannot attend any meetings, he knows AA members are there and that he can count on them and assist them in return. In AA, Christian has found a philosophy of fellowship, simplicity and equality. A motto that does not come from AA frequently inspires him: "Not simply to succeed in life, but to make a success of your life."

Ann X and Mary Y: Coping with Mental Illness

During the past ten years, groups that help parents and friends of people with mental illnesses have been established in many Canadian cities. The groups include Friends of Schizophrenics, the Association of Relatives and Friends of the Mentally Ill,

and many others with similar names. They are usually established by parents, often with assistance from local volunteer organizations or associations like the Canadian Mental Health Association. These groups often decide to band together in a federation or provincial association.

One such a group was established early in the 1980s, thanks to the efforts of two mothers, Ann X. and Mary Y.

When her son was diagnosed as schizophrenic at age 18 and hospitalized for the first time, Ann felt desperate and began seeking help and information. She felt her lack of knowledge acutely, particularly about how to respond to the illness and crises her son was going through. She had heard about a group of parents and friends of the mentally ill in her city. She telephoned, hoping to speak to a parent. The person who answered was unfortunately not a parent and asked Ann to leave her telephone number so that someone could call her back. But Ann did not want to risk having her son answer. Although she knew when the group met, she hesitated to go.

Finally, several months later, through the good offices of the volunteer bureau in her community, Ann met Mary, who also had a mentally ill child. The volunteer bureau was ready to help them establish a self-help group for parents and friends of the mentally ill. At first the two women thought of joining an existing parents' group in another part of their city, but they finally rejected the idea. They knew they could count on the support of their local volunteer bureau which had already helped set up a self-help group. In addition, they could count on other invaluable forms of help: someone to take calls, free premises, and access to a photocopier.

Ann and Mary organized their first meeting and publicized it in the local papers. More than two dozen people showed up. Most were concerned parents, but a psychiatrist and a nurse from a local hospital also came. The participants expressed their sense of isolation and helplessness, and they voiced a need for information and services. Two of the main objectives that have continued to guide the group over the years surfaced at this first meeting. The

first was to offer mutual aid to parents and friends of the mentally ill by sharing and discussing their difficulties and keeping members up to date on available community resources. The second objective was to improve community conditions and establish certain services.

It was apparent that the one hospital psychiatric ward in the community could not meet the rising demand created by a growing population while the level of professional resources remained unchanged. The members' desire to meet and help one another was strengthened by their dissatisfaction with the inadequacy of local resources and the exclusion of parents from the therapeutic process.

A twelve-member board of directors was set up, composed of nine parents, the director of the volunteer bureau and two volunteers who wanted to work in the area of mental health. The board of directors rapidly gave itself an organizational structure, drafted by-laws, registered the group as a non-profit organization, and produced a pamphlet explaining the objectives and activities of the group. Each member took on a responsibilty, such as communicating with the media, answering the phone, keeping the membership list up to date and providing secretarial services.

From the start it was important to Ann and Mary that the group appear well organized as this would increase their chances of being taken seriously.

The group offers an open meeting to parents and friends once a month. At these meetings there is generally a facilitator or speaker who may be a professional working in the mental health field, a lawyer, or a representative from a community organization with similar concerns. Sometimes the leaders are group members. After the main activity, light refreshments are served; veteran and new members have a chance to get to know one another better and to share additional personal experiences.

For its part, the board of directors meets once a month to discuss organizational and advocacy matters. Some of the parents in the group are also on the boards of other community organizations, positions that have enabled them to assist in setting up

community services for the psychiatrically ill and in forming a provincial federation of groups with a similar interest in the mentally ill. It is interesting to note that several parent board members believe that what has helped them most has been the experience of sitting on the board of directors; their work seems to have given them an outlet for their energy and frustration.

The monthly meetings undeniably give participants useful information and invaluable support. The group makes every effort to make new members feel comfortable about attending meetings without feeling guilty. The members are anxious to discover everything that can be done to prevent sufferers of mental disorders from deteriorating further and to reduce the negative impact on families. Some people come only once, discouraged perhaps by the fact that the person with the mental disorder does not seem to get any better. Others, however, soon find the group the ideal meeting place and would not miss the monthly meetings for the world.

Such was the case with an elderly couple who had been living for years with their schizophrenic son, now an adult; the couple had never had a chance to share their difficulties. The mother had discovered this support very late in her life but felt so grateful to the group that for a long time she would offer to phone all the members to remind them of upcoming meetings. She died recently, but her husband continues to attend all the monthly meetings, which have become like family gatherings for him. He occasionally phones other members to keep them informed of major events in his life.

The group has enabled many members to form new friendships based on sharing and respect. "We feel more comfortable together than we do with our families or childhood friends," says Ann, the co-founder of the group. "I find that a group like this gives me information, support, and the chance to help others," she adds.

In just a few years, and despite very limited resources (a few small donations), the group has managed to carry out many projects inspired by the twin goals the organization adopted at its inception:

- to provide information and opportunities for self-help to concerned members of the community through monthly meetings;
- to assist in the establishment of new services within the community and to help shape provincial policies on mental health.

At present the group is hoping to obtain a grant that will enable it to hire a part-time staff member.

3

The Characteristics of Self-Help/Mutual Aid

Without describing the activities of self-help groups in detail, in this chapter we highlight the traits shared by these diverse groups, thus addressing several major issues. First we examine whether the men and women who belong to these groups or establish them have anything in common. We will see how the experience of suffering and feeling victimized is common to all group members.

We also seek to understand the principles of mutual aid. Under what conditions do people turn to mutual aid? What factors promote it? What are the characteristics that enable veteran members to gain as much from mutual aid as do the newcomers?

We look at the role of common experience and the feeling of equality among group members. We also clarify the voluntary aspect of mutual aid.

Finally, we examine the concept of helper-helpee and conclude by defining self-help groups.

Mutual Aid in Self-Help Groups

What is the exact nature of the mutual aid practised in self-help groups? Researchers who have observed these groups and studied

how they work have identified a number of characteristics that underlie groups' activities and helping processes. Findings vary greatly with the type of group observed. Chapter 7 provides a summary of the different mutual aid mechanisms and their effectiveness.

What conditions must exist for self-help group members to practise mutual aid? We will answer this question by describing the conditions that are common to all these groups, then propose three major characteristics typical of members of self-help groups and their mutual aid activities.

The mutual aid practised in groups can take two distinct forms, personal and collective. A clearer picture of the two forms emerges as we look at various situations where mutual aid is practised.

Since mutual aid consists of reciprocal assistance, it can be seen as a form of help. Help is, above all, someone acting for another's benefit by supporting that person's efforts. Mutual aid is therefore a shared process that benefits at least two people.

Mutual aid brings to mind different images. We think of the groundswell of fellowship that impels individuals, groups or communities to help one another in the wake of natural disasters such as floods, earthquakes, tidal waves, drought, famine, or fire. We also think of people working together to carry out projects to ensure the survival and development of the human race. This form of mutual aid and its evolution through the ages in different societies and cultures has been well described by Kropotkin in his book *Mutual Aid: A Factor of Evolution*, first published in 1902.[1]

Kropotkin deals mainly with mutual aid as a collective phenomenon. He begins with mutual aid and co-operation among animals and the role it plays in their survival and development, drawing on studies by zoologists and his own observations and studies in Siberia. He goes on to list the many forms mutual aid took in primitive societies, in medieval cities, and in late nineteenth-century society.

Having lived in Russia under the czars, Kropotkin shared the suffering, misery and abuse to which many of his fellow citizens

were subjected. A prince by birth, Kropotkin adopted revolutionary ideas; he claimed that the centralization of power had suffocated the aspirations of the common people and destroyed all kinds of associations formed through co-operation and mutual aid. He regarded mutual aid as an instinct that had played a more crucial role in the survival and development of the human race than mutual struggle, though he recognized that struggle also played a central role in the evolution of species.

Kropotkin's examples focus on collective rather than personal mutual aid. He is interested in how group members share tasks and act collectively to carry out common projects. We call this type of activity *collective mutual aid*.

Collective mutual aid can take different forms within self-help groups. Besides the planning of regular activities and meetings, groups can also organize social activities, such as dances for single parents. Collective mutual aid can also lead to activities aimed at promoting social change, such as the establishment or improvement of services.

Mutual aid can also take the form of *personal mutual aid*, which usually does not involve collective projects and operates mostly from one person to another. The personal mutual aid practised in groups focuses primarily on behavioural, emotional and attitudinal problems experienced by one person. This personal mutual aid can result from sharing between two group members or between a member and the rest of the group. It is often a form of psychological help, providing emotional support through sharing experiences, information, and ways of coping.

The mutual aid practised in self-help groups thus generally operates at both the collective and the personal levels, but it is personal mutual aid that distinguishes these groups and remains their primary purpose.

Collective and personal mutual aid are doubtless as old as humanity. During the past fifty years, however, a new element has been added: personal mutual aid is now practised in a wide range of groups formed specifically to help individuals deal with particular personal problems. In North America, the growing self-

help/mutual aid movement traces its roots to the founding of Alcoholics Anonymous in 1935 and the establishment of Recovery, a group that assists former mental patients, in 1937.

In the balance of this chapter, in discussing the context and characteristics of mutual aid, we refer both to personal and collective mutual aid in groups, putting the emphasis on its personal aspect.

Suffering: What Triggers Self-Help/Mutual Aid

People turn to mutual aid during crises or periods of great difficulty. The common element in these situations is suffering; whether conscious or subconscious, this seems to be the deciding factor that triggers mutual aid.

Suffering can occur at any stage of one's life and can have many causes: the death of a loved one, illness or accident, old age, disability or handicap, any kind of separation or, in a more general sense, any unsatisfied basic need such as our needs for security, love, a sense of belonging and self-esteem.

The feeling of being a victim, often associated with suffering, also impels people to turn to mutual aid. People may consider themselves *victims of fate* (which often leads to passivity) or *victims of themselves, victims of others,* or *victims of ignorance.* The relative importance attached to these last three kinds of victimization (oneself, others, ignorance) determines the degree to which different self-help groups emphasize personal change, social change, or new learning.

In the face of suffering, people often feel isolated, rejected or excluded, as well as victimized. The importance of personal mutual aid and belonging to a group is therefore easy to understand; here a person feels accepted and understood, and one's sense of isolation is reduced.

Suffering involves both psychological and physical pain. It is often difficult to draw the line between the two; they are often closely linked, with physical health affecting psychological well-being and vice versa. Thus emotional difficulties stemming from

insecurity, lack of affection, or loneliness may provoke or aggravate physical problems commonly known as psychosomatic illnesses. Conversely, physical illness may give rise to states of fear or anxiety.

Mutual aid and self-help groups are particularly concerned with mental suffering and its associated behaviours. Mutual aid therefore has a special role to play in improving mental health. Even self-help groups such as OSTOP, which deal with chronic illnesses and are concerned primarily with physical health, do not neglect behaviour and the impact of physical illnesses on social relationships. Indeed, in the case of people suffering from chronic illness, attitudes toward the illness are very often fundamental in preventing deterioration and maintaining health. Self-help groups for people with chronic illnesses provide substantial support for maintaining and improving health.

Associations, recreational clubs, co-operatives with economic interests, and many other voluntary organizations practise mutual aid. Such groups do not meet our definition of self-help groups, however, unless they work to alleviate suffering, which is the principal motivation in the mutual aid we are discussing here.

In certain circumstances, however, suffering is not explicit or conscious. In fact, many people do not even realize they are suffering, that they are in pain. Revealing suffering, even if it is only a few tears, is seen by society as an act of weakness, particularly for men. But suffering is there all the same.

The mutual aid we are examining therefore seeks to eliminate or reduce suffering. Let us now consider the central characteristics of mutual aid as practised by self-help groups.

The Three Characteristics of Self-Help/Mutual Aid

Three characteristics are necessary to the practice of mutual aid in a group. Each plays a key role in enabling self-help groups to initiate and carry on their activities.

The first characteristic is the common experience shared by group members and the resulting resonance that develops. The

fact that participation is essentially free constitutes the second characteristic. The third is the willingness of "self-helpers" to accept one another as equals.

To understand these characteristics, we need only recall instances of mutual aid that most of us have received from schoolmates, brothers and sisters, or others during a crisis.

Common Experience and Resonance

The common experience we are referring to here concerns particularly the nature of certain kinds of suffering. Thus it may involve two people who have experienced or are experiencing similar difficulties with alcoholism or a chronic illness which is affecting their lives.

Mutual aid is triggered not only by a common experience of suffering, but also by similar feelings about that suffering. The experiencing of reciprocal feelings by two people is called *resonance*. A newcomer in a self-help group who establishes feelings of resonance with a veteran group member eventually tends to identify with the veteran. This identification is an important factor in the helping process, as it enables the new member to feel less isolated, to face certain fears, and to regain self-confidence.

Without a doubt, this common experience and the resonance it gives rise to are the most powerful factors which trigger mutual aid. It is through resonance that two people get on the same wavelength, allowing them to feel the pain of the other and express their compassion.

Resonance between two people evolves as they practise mutual aid. Thus, an initial resonance may be felt when two people discover they have the same rare disease. As these people get to know each other, they discover that they have other points in common that strengthen the initial resonance, such as negative feelings of anger or rebellion, but also positive feelings or similar plans they want to carry out to overcome their suffering.

In addition to the common experience of pain or suffering and its many manifestations and consequences, other factors may foster resonance between two people: the time and context of their

first meeting, similar or complementary character traits, values, professional interests, and intellectual, cultural and spiritual affinities.

While common experience creates the initial resonance that triggers mutual aid, it is the sharing of this experience and its exploration that enriches and deepens resonance, thereby favouring the continuation of mutual aid. It should be noted, however, that sharing experiences — even when they are strikingly similar — does not necessarily lead to resonance. For example, two people wanting the same job may feel strongly competitive and antagonistic toward one another despite their similar experience.

In a relationship of personal mutual aid, one person will often voice his or her pain, or relate the specific difficulties of the crisis at hand, while the other listens with compassion. This *compassion*, which is simply the ability to share someone else's suffering, appears to spring from resonance. It is all the more natural to the self-helper in that he or she has already experienced similar difficulties or pain. Compassion is openness to another's suffering; thus, mutual aid begins its work through words, attitudes and behaviours inspired by resonance.

Self-Help is Essentially Free

Mutual aid is a *voluntary* activity, meaning that it is freely given and free of charge. Someone who aids another in trouble while practising mutual aid expects no remuneration. Nor does the helper expect any other form of direct compensation from the sufferer, though the helper usually gains some personal benefit, such as a deeper understanding or stronger self-esteem.

The notion of free help calls for a few explanations. In self-help groups, as elsewhere in life, one group member will often help another without the slightest expectation of receiving help in return. At the same time, people hope to receive help when they too need it, even if it is not expected immediately or directly from the beneficiary of their help. In this regard, mutual aid in self-help groups resembles mutual aid in families; we expect help with our

problems from other family members, but not necessarily from the same family members we have helped in the past.

In addition, free help means that self-help groups do not pay professionals for help provided within a group. Despite this general rule, some self-help groups may decide to call on a specialist who may be paid for helping the group. In other instances, professionals from the health and social services field have helped set up groups or advise them as part of their professional activities, for which they are paid by their institutions or agencies such as local social service centres, community centres, hospitals and the like. Whether groups should seek help from professionals is a tricky question, because the mutual aid method of operating is so often at odds with professionals' training that there are still few professionals who appreciate what self-help is all about.

Mutual aid is exercised freely. In other words, it is not prescribed or demanded by an authority or law; neither is it controlled by organizations or institutions other than the self-help groups themselves.

In short, mutual aid is a voluntary activity. Like any other volunteer organization, however, a self-help group may occasionally hire people to perform specific tasks if it has the money. In doing so, each group must ensure that its autonomy is maintained and that its mutual aid activities are not adversely affected.

A final point concerns the flexibility of voluntary help. While self-help group meetings are generally held at set times, members may seek help from one another at any time, an invaluable advantage in times of crisis.

Equality

Equality, the third main characteristic of mutual aid, is difficult to define. It concerns both the attitudes and behaviours of members toward one another in responding to pain and to the consequences of suffering. Equality consists of accepting one another and behaving as equals by setting aside differences which are generally considered superficial and irrelevant to mutual aid relationships.

Members of many self-help groups recognize and understand the tremendous importance of equality. They know that help through mutual aid derives all its power from the feeling of equality between the helper and the helpee.

The feeling of equality arises largely from the experience of suffering or enduring a crisis. Two people who have experienced similar crises tend to treat each other as equals, whatever their differences. The spirit and practice of equality are reinforced or intensified by mutual aid and the resonance that accompanies it.

Common experience by itself does not automatically engender a feeling of equality; not even common experience and resonance together necessarily do. Resonance, which may have been established on the basis of similarities between two people, may develop into a relationship of complementarity, such as the one that exists between teacher and student; in such cases feelings of superiority and inferiority may arise to compromise the notion of equality. Such risks are well recognized, particularly by Alcoholics Anonymous and other groups inspired by similar principles. To reduce the risk, principles have been laid down so that dependency relationships can be avoided, particularly between self-helpers and the new members they are sponsoring.

Another kind of difficulty may arise if a new member of a self-help group has trouble feeling equal to the other members. New members often feel isolated and guilty and are overpowered by many reactions and negative emotions; this may make them feel inferior. Longer-term members, who have more experience in overcoming such difficulties, are in a better position to accept newcomers as equals. Thus, when they first join a group, new members may be more conscious of receiving help than of interacting as an equal and giving others help. Until new members realize that they too can help, it is often difficult for them to feel equal to the others.

In reality, however, members of self-help groups do not always live up to this enviable spirit of equality. The self-help experience arouses feelings of solidarity and equality, but these feelings can be dampened by everyday life or simply by the decisions and ad-

ministrative tasks involved in running the group. Repeated practice of mutual aid helps, however, to restore those feelings of solidarity and equality.

The Helper-Helpee

The foregoing description illustrates an important aspect of how self-help groups work and the snowball effect they achieve. At first new members receive support from other group members. Later they discover their own capacity for helping and develop a feeling of equality with other members. By participating in the group, they are able to play the role of helper-helpee (also referred to as *self-helper*), a person who, being conscious of his or her capacities and needs and those of others, knows how to give and receive help at the same time. It is through the practice of mutual aid that the self-helper in his helper role is able to accept the person receiving help as a true equal; there is no place for feelings of superiority or inferiority. It is senior members, or veterans, who most often play the role of helpers in a self-help group.

This description of the self-helper reveals a fundamental characteristic of self-help that makes it unique among the helping methods and is responsible for so much of its success: even as a self-helper assists another, he or she is also receiving help. In day-to-day life, we tend to consider that one person (the *helper*) gives, and the other (the *helpee*) receives. The magic of self-help is that the self-helper simultaneously gives *and* receives. We explain this phenomenon in the next chapter in discussing human motivation.

A Definition of Self-Help Groups

In light of the characteristics described in this chapter, we offer the following definition of self-help groups:

> *Self-help groups are small, autonomous and open groups that meet regularly. As a result of a personal crisis or chronic problem, members share common experiences of suffering and*

meet each other as equals. The primary activity of these groups is personal mutual aid, a form of social support that focuses on the sharing of experiences, information and ways of coping. In addition to personal change, members often engage in activities directed to social change. Group activities are voluntary, and essentially free of charge.

This definition corresponds with definitions proposed by other authors[2] and with the one put forward by the recently established North American Self-Help Clearinghouse Network. It adds three new elements, however. The first is that personal mutual aid is considered the primary activity of the group. The other two elements essential to the self-help process are the common experience of suffering and the feeling of equality. In addition, two other aspects of self-help groups should be explained.

Self-help groups are open to all, signifying that they are, by their nature, ready to accept new members. Self-help groups are also small, often with twelve to twenty members. To avoid becoming too large, they often form new groups. Often the groups have open sessions that anyone can attend and closed meetings for those already familiar with the group's way of operating.

Finally, some self-help groups devote almost all their activities to personal mutual aid, whereas others also work to bring about social change. Members of the second type of group fight for the establishment or improvement of social programs and policies, or promote the point of view of the user or consumer of such services. In these instances, groups may evolve to such an extent that they begin to concentrate entirely on social activism or advocacy. It then becomes an advocacy group, or even a political group, and is no longer considered a self-help group by our definition.

Our definition may seem incomplete to some in that it excludes important characteristics (such as sponsorship or the "buddy system") vital to the functioning of many groups. We have deliberately limited our definition to those characteristics common to *all* self-help groups.

Finally, the definition's sober tone should never obscure the extraordinary human warmth present in self-help groups. As the

case histories in Chapter 2 show, groups often become a new kind of family for their members. All kinds of contacts take place between members in addition to those that occur during meetings. Members usually do not call for help only during crises; people may call simply to pass on good news or to chat, or visit one another as they would family or friends.

References

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4

Motivation and Dynamics of Self-Help

In this chapter, which is more theoretical than the preceding ones, we take a closer look at the concept of personal mutual aid and its practice in self-help groups.

The characteristics described in the preceding chapter represent the conditions that must exist for mutual aid to occur. Here we will consider other features or consequences of mutual aid. Of course, those in the best position to fully understand and appreciate the nature of mutual aid are group members.

Maslow's model of the hierarchy of human needs is used to explain the motivations behind mutual aid and the forces that attract new members, retain veteran members, and impel them all to practise mutual aid. We use this theory of human motivation as a framework for describing and understanding the nature and dynamics of self-help.

In the final section of the chapter we elaborate on the framework provided by Maslow's theory by describing the role suffering plays in leading people to mutual aid. The framework explains the dynamics of self-help/mutual aid and its snowball effect which has led to the substantial growth of self-help groups and networks.

Features of Personal Mutual Aid

Two features of personal mutual aid which we will discuss in more detail below were mentioned in the previous chapter: autonomy and the magic of self-help. Here we introduce the concepts of symmetrical and asymmetrical mutual aid to gain a better understanding of the exact nature of the mutual aid that takes place between two people.

Although our focus is personal mutual aid as practised in groups, interpersonal mutual aid outside groups, such as interactions between friends, can yield similar benefits. But the interaction between a group member and the group as a whole is an important form of mutual aid and adds a whole new dimension to mutual aid. Such interaction occurs, for example, when a member has the courage to relate his or her story in front of the group and receives applause and other signs of recognition and respect from listeners.

Symmetrical and Asymmetrical Mutual Aid

Mutual aid can take the form of a symmetrical or an asymmetrical exchange. A mutual aid exchange between two people is *symmetrical* if both have given and received comparable help and if the exchange has focused equally on the difficulties of both. In these instances, each listens in turn to the other and tries to give the other the best support possible.

By contrast, a mutual aid exchange can be termed *asymmetrical* if the dialogue between the two people is centred solely on the difficulties of one person, the helpee, while the other plays the role of helper.

The concept of asymmetry permits us to understand that although mutual aid is not always perfectly reciprocal, it nevertheless always implies a strong reciprocity: the person being helped has basic personal needs satisfied while, at the same time, the act of helping satisfies personal needs for the helper. This phenomenon, referred to as the magic of self-help, is discussed later in the chapter.

Mutual Aid and Autonomy

Practising mutual aid fosters the development of autonomy in both the helpee and the helper. The mutual aid offered by a senior group member who has experienced similar difficulties, succeeded in overcoming them, and who shares his troubles and successes helps others to take control of their lives or regain their lost autonomy. Lindy, whose story appeared in Chapter 2, is such a role model. She continues to inspire many of the members of OSTOP, the group she founded.

Feeling accepted as an equal by one's helper is a powerful stimulus, strongly motivating the recipient of mutual aid to become more autonomous. Indeed, the relationship of equality that develops through mutual aid precludes relationships based on differences in rank or knowledge, or relationships based on dominance and submission that tend to create dependencies. Self-help groups have ways of lessening the risk of dependency. At Alcoholics Anonymous, senior members may speak to the group about the benefits of sobriety, but they also regularly mention the failures, lapses and relapses they have experienced as they progressed toward sobriety. When new members hear such testimonials just after a relapse, they regain hope and are assured that their hope is realistic because theirs have not been the only lapses or relapses. At the same time, the senior helper is reminded of his or her function as a role model, which reinforces the veteran's autonomy.

It is true that in self-help, as in other kinds of help, the person being helped may at times follow suggestions from a trusted helper. In the long run, however, any self-helper worthy of the name will help the helpee to become autonomous. This philosophy is clearly demonstrated in the second case history in Chapter 2. Christian talked about Gilles, a new AA member who had received a lot of support and attention from the other members of the group, and to whom Christian had to say one day: "Gilles, you'll have to learn to stand on your own two feet."

The Magic of Self-Help

The phenomenon we refer to as the magic of self-help is at the heart of self-help and mutual aid practice. It has been described and explained by various authors in various ways; it was already part of AA's literature more than 30 years ago.[1] Riessman, an American self-help pioneer and author, dubbed it the "helper therapy principle," meaning that one helps oneself by helping others or that the help one offers others is therapeutic.[2]

This principle — helping ourselves by helping others — has certain parallels with many teachers' experience: we learn, or at least deepen our knowledge, by teaching. This principle may astonish someone who has never been aware of, or experienced, it. The same principle applies somewhat to professional and voluntary help. The mutual benefits are in most cases far greater with self-help because of its characteristics of common experience, resonance, and equality.

The magic of self-help can be defined in terms of Maslow's theory of human motivation, a theory which proposes that basic human needs can be ordered in a hierarchy.[3] In the process of helping someone else, a self-helper satisfies several of his or her own basic human needs: self-esteem, a sense of belonging, affection and acceptance, and security. Because satisfying our own basic needs constitutes a form of helping ourselves, it becomes clear that the magic of self-help lies in "helping oneself by helping others."

This magic is particularly noticeable in groups where members have the chance to learn or practise the art of sharing their life experiences and the wisdom they have acquired, commonly referred to as "experiential knowledge."[4]

Thus self-helpers often become specialists in their fields of "experiential knowledge," and feel all the more appreciated because they can help others by sharing this knowledge.

Human Motivation and Personal Mutual Aid

Maslow's theory of human motivation integrates a vast series of findings from various studies and observations.[5] The theory is particularly successful in incorporating the insights of psychoanalytical studies on conscious and subconscious motivations. The theory's basic concepts are simple, but they quickly become complex as we explore their ramifications further.

In the next section we present a brief overview of Maslow's theory to illustrate the driving forces behind mutual aid and the motivations of self-helpers.

Basic Human Needs

Maslow divides human needs into five major hierachical categories. Certain needs predominate, influencing our behaviour more strongly than others; in other words, they motivate us more. If we are trying to fulfil two needs at the same time, it is helpful to know to which we are likely to give priority. Once primary needs such as hunger have been satisfied, other needs surface. Similarly, once these new higher-order needs have been satisfied, they give way to needs of a still higher order, and so on. Maslow has succeeded in sorting the multitude of human needs and desires into five major categories and in ordering them according to a hierarchy that is coherent and compatible with all we know about human behaviour and motivation.

The first and predominant order of needs, situated at the bottom of Maslow's pyramid, consists of *physiological needs* such as thirst and hunger. Thus, if we find ourselves in a situation of extreme privation, our primary motivation will be to satisfy our physiological needs first. Someone who lacks food, security, love, and self-esteem will try to obtain food first.

Next come the *needs for security*, which emerge only when our physiological needs have been reasonably well satisfied. Security or safety takes many forms and includes stability, reliability, and

protection; the absence of fear, anxiety or chaos; the need for structure, order, law, limits, and so on. Until our needs for security and protection have been satisfied, they take precedence over all other needs, including even physiological needs which, if they have been sufficiently satisfied, become undervalued.

At this point needs of the third order appear, *the needs for belonging, love and affection*. Someone with these needs will suffer greatly from the absence of friends, a partner, or children. Such people feel a strong desire for affectionate relationships with others and a place in their group and family.

The *needs for esteem* come fourth and include self-esteem and the esteem of others. Self-esteem includes the desire for strength, achievement, competence, control, confidence in facing the world, independence and freedom; the esteem of others includes the desire for a good reputation, respect and status.

Finally, the fifth order is the *need for self-actualization*, which surfaces only when all other needs have been sufficiently satisfied. This ultimate need takes widely varying forms and consists of the desire to fulfil one's potential to the highest degree, to become everything one is capable of being and, finally, to be at peace with oneself.

Maslow noted that the need for security is felt above all other needs in times of danger, emergency and chronic troubles. When chaos threatens, most people neglect higher-order needs and begin to give precedence to the need for security.

Maslow cautions that his hierarchy must not be adopted too rigidly and that exceptions do occur. Higher-order needs sometimes surface before lower-order needs have been entirely satisfied. Most people in our society have basic needs that are partly satisfied and partly unfulfilled. According to Maslow, it is as if the average citizen were 85 per cent satisfied as far as physiological needs go, 70 per cent satisfied in terms of security, 50 per cent satisfied in the need for love, 40 per cent satisfied in matters of self-esteem, and 10 per cent satisfied with his or her self-actualization. Even if these figures are arbitrary, as Maslow himself

concedes, they give a good idea of the relative ranking of the five basic needs.

Maslow's theory can be criticized for its imprecision, but it does serve as a useful frame of reference for explaining the motivation in mutual aid.

Motivation in Self-Help/Mutual Aid

When a veteran group member helps a newcomer, they are engaged in asymmetrical mutual aid. Through this help, the person being helped can satisfy three major categories of needs: the needs for security, the needs for belonging and affection, and the needs for self-esteem.

Someone confronting a crisis or serious difficulty feels an abruptly heightened need for security. For someone who had been feeling quite secure, it can come as a great shock to be suddenly assailed by all kinds of fears, each reflecting different kinds of insecurity. Through their mutual aid activities and the bonds they foster, self-help groups enable members to satisfy their need for security, acceptance, affection and self-esteem. Two characteristics of mutual aid groups — the common feeling that resonates from shared experience and the feeling of equality — contribute greatly to the fulfilment of diverse needs. Identification with other members and the common understanding that arises among members contribute to the feeling of belonging and diminish the fear of loneliness. Moreover, the sense of equality new members feel helps them take control of their lives and develop a stronger sense of self-esteem.

The initial motivation to seek help, whether conscious or subconscious, is generally a response to the lack of fulfilment of one or several basic needs. Thus, a parent who has just discovered that his child is schizophrenic may be motivated by insecurity, but also by feelings of guilt and low self-esteem. A homosexual, on the other hand, may be drawn to mutual aid by a need to belong, a need that may have arisen from an overwhelming sense of being rejected by society.

As for the widow or widower, the need for security, affection

and belonging may be the principal motivating agent along with the need to establish a new social identity. The need for security may take different forms, such as a lack of confidence in dealing with everyday chores like shopping, cooking or cleaning, or insecurity about financial, material or emotional needs.

The motivation of the veteran self-helper may be somewhat different, but he or she also succeeds in satisfying the same three basic needs, though in a different way.

The veteran self-helper, who has known and overcome crises or illness, generally has a less acute need for security than a new group member, having already faced most of the fears and other symptoms of insecurity. Instead, the veteran self-helper seeks through the helping process to satisfy the need for esteem, belonging and affection. Such is the case of Christian L., the AA member we spoke of in Chapter 2.

In practising mutual aid as a sponsor, Christian helps new members by relating his experience of alcoholism, by giving them information, and by offering emotional support in the form of listening with warmth, understanding and acceptance. For him, giving support is also a way of measuring the progress he has made, and of confirming the new strengths, abilities and confidence he has succeeded in achieving. In addition, by talking to a group about his experience as a non-practising alcoholic, Christian gains the esteem and admiration of those he helps.

The need that self-helpers undoubtedly satisfy most frequently is the need to belong and to make friends. Christian rightly declared that AA is a real family that has given him genuine friends.

Belonging to a self-help group continues to fulfil the veteran self-helper's need for security in two ways. First, by helping others with the same difficulty, senior members gain a better understanding of themselves and discover new ways of coping, thus increasing their inner resources and sense of security.

Second, members know they are part of a support network they can call upon if needed, an important consideration for members of AA, since alcoholism is considered a life-long disease and

members must renew their efforts to stay sober every day. We saw in Chapter 2 how Christian uses the network.

Like other group members, senior members sometimes need direct help; in such cases, they may contact another group member or even turn to the whole group. As discussed earlier, however, self-helpers satisfy their own needs by receiving while they give. This magic of self-help gives the self-helper the sense that something unique is occurring, because in everyday life, we are accustomed to giving and receiving separately, not simultaneously.

In mutual aid exchanges, then, self-helpers satisfy particularly three of the five basic needs alternately or simultaneously. A person whose three basic needs — security, belonging and affection, and esteem — are satisfied can be considered in sound psychological health.

In this chapter, we have not examined the activities and helping methods of self-help groups in detail. This is the focus of Chapter 7. Links could then be established between the basic needs satisfied by mutual aid and the activities and helping methods identified by researchers who have studied mutual aid. Quite apart from the activities specific to each group, the simple fact of participating in activities and having relationships with others is an important helping factor, for it automatically begins to satisfy the need for belonging and security.

There is a continuing need for studies to define more clearly which activities of self-help groups provide effective help and why they are effective. Some information on the subject is known (see Chapter 7).

The Dynamics of Self-Help

What explains the growing attraction of self-help groups? Why do people form them or join them, sometimes devoting months and even years to them? What forces impel new members to join and veteran self-helpers to stay?

Several social forces are at work here. We limit ourselves, however, to examining the forces that operate on a personal level,

using the theory of motivation just outlined and the concept of suffering examined in the previous chapter.

The dynamic is relatively simple: the three basic human needs act as forces pulling the individual forward, while suffering (which also takes three basic forms) pushes the individual in the same direction.

We should recall that the three forces of attraction will be of little concern to people whose basic needs for food, shelter, and warmth have not been adequately met. Apart from these extreme cases, however, these three forces are part of every human being, often lying dormant while we remain unaware of them or ignore them, allowing ourselves to be caught up by other forces that pull us into the tumultuous world of achievement, prestige and social success. At any moment, however, a crisis or upheaval can throw our entire existence into question; this is when these basic human needs, particularly the need for security, make themselves felt.

What are the three forces of suffering that can motivate a person in crisis? Suffering usually spurs its victims to action. The nature of that action, however, depends to a large degree on the victim's interpretation of his or her suffering. Thus, some people react by taking a tranquillizer. Others base their reactions on the relative importance they attach to the three major sources of suffering — *oneself*, *others*, and *ignorance*. If they consider themselves and their behaviour, attitudes, emotions and thoughts to be the main source of suffering, they will emphasize the need for personal change. If others are thought to be the cause of suffering, a person may advocate change in the immediate environment or broader social change. If people feel ignorance is the problem, they will emphasize education, information and research as the means of resolving the problem and putting an end to their suffering.

It is often tempting to attribute suffering to a single cause; the struggle looks easier because all we have to do is tackle the problem in question. In reality though, as with illness, suffering often has no single cause, but rather multiple causes. Accordingly, to alleviate or eliminate the suffering associated with a given situation, it is generally necessary to address a host of factors or causes

at the same time. Self-help groups understand this; however, enlightened by the experience of their members in handling past crises, they understand that it is often more effective to address one factor at a time.

This is why many self-help groups, recognizing how difficult it is to change certain behaviour such as alcohol or drug addiction, concentrate on the various stages of personal change.

To the members of these types of self-help groups, it appears to be more effective to work on their own behaviour, with the support of others engaged in the same personal struggle, rather than expending energy attempting to change the behaviour of people around them or to change social structures.

For other groups, however, such as those for people whose problems are related to social identity, it is more important to fight for recognition, acceptance and respect. Such is the case for many women's groups, disabled people, gays and lesbians, and former psychiatric patients. The force that motivates these group members is the desire for freedom — freedom from control by others and freedom from dependencies on professionals or others in their social milieu. The founding members of these self-help groups attribute their suffering to a combination of control and dependency, and they therefore seek to take charge of their lives by fighting all abusive control on the part of others.

Ignorance, the third source of suffering, is attacked in at least two ways. The approach adopted by groups for people suffering from chronic illness, for example, is first to provide sufferers with information and appropriate services, and second, to promote research into better means of controlling or treating the illness.

In our view, these three sources of suffering are the main forces motivating people facing a crisis or upheaval, compelling them to seek out fellow sufferers. The common experience of suffering, it appears, is the composite reality created by multiple difficulties, past and present pain, and the self-helper's interpretation of the cause of his or her distress. A self-help group's *ideology* depends in part on its members' interpretation of their common suffering.

Judging by the activities of diverse groups that promote per-

sonal change, social change, education and research, self-helpers are often motivated by a combination of the three forces.

A self-helper's interpretation of his or her suffering, as well as the relative importance of each of the basic sources of suffering, may evolve over time. Thus, although primarily concerned with personal responsibility first and foremost, the self-helper will later discover the role played by others as well as the impact of lack of knowledge. Often it is the group that allows the self-helper to achieve harmonious personal development. In other cases, the self-helper finds it more useful to pursue that goal outside the group.

In summary, suffering and the common experience of suffering constitute the main forces motivating the self-helper. Suffering in turn can be broken down into three distinct forces that nevertheless often work together.

Returning to our earlier illustration of the dynamics of self-help, the self-helper is simultaneously pulled forward by one set of forces and pushed forward by another, in combinations that vary according to the self-helper's stage of development. A common example is the new member who is only attracted by the need to alleviate or eliminate his or her suffering by changing certain behaviours or attitudes.

The dynamics of self-help can therefore be seen as an extension of the magic of self-help. Through membership in a self-help group — often over a period of many years — self-helpers can often satisfy a number of their basic needs and their desires for personal growth, social change and the acquisition of knowledge.

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5

Personal Health

In this chapter we review the evolution of the concept of health and propose a model for health promotion that focuses on the person and on the five main resources people can use. We pay special attention to the concepts of self-care and personal health. Finally, we explore the importance of self-help groups in personal health.

The Concept of Health

Psychological suffering, the usual context in which mutual aid occurs, is closely linked to our state of health. Some suffering results from poor mental or physical health. Accidents, chronic illness, or the simple back pain so common today certainly cause physical pain, but they usually create emotional anguish as well by preventing people from carrying on the activities they enjoy. Similarly, mental suffering and pain, such as mourning, separation or work-related stress, can trigger psychological difficulties, such as depression, as well as physical problems. For example, excessive and prolonged stress at home and work may lead to over-drinking or chain-smoking, which in turn can lead, two or three decades later, to cirrhosis of the liver or cancer.

These few examples show the links between suffering, illness, and health, both mental and physical.

The main topic of this chapter is the role of self-help and mutual aid in health, but to provide a context for that role we offer a brief review of the recent evolution of the concept of health, with particular reference to our knowledge of several major factors that influence health. Health is not simply the absence of illness or disability; rather, it can be defined as a state of complete physical, mental and social well-being — a definition the World Health Organization adopted some time ago. In 1974, based on the results of various studies in social medicine, the government of Canada published a white paper offering a new outlook on health and suggesting that health was influenced by four main categories of factors: human biology, the environment, lifestyles, and the organization of health care.[1] The paper emphasized that health does not depend solely on health care institutions (hospitals, community centres or clinics) or on professional health care workers (doctors, nurses and others), but also on our environment and our lifestyles.

Numerous experiments and studies have been carried out in various countries to identify and test the most promising approaches to improving health. The concept of *health promotion*, defined by the World Health Organization as "the process of enabling people to increase control over, and to improve, their health," finally emerged as a central concept.[2] At the same time, a Canadian document published in 1986, and based on studies conducted and knowledge gained in the previous ten to fifteen years, proposed a new framework for health promotion.[3] This document, which is addressed to individuals, groups, professionals and governments, focused on *three essential mechanisms* for the promotion of health: the individual assuming responsibility for his or her own health, or self-care; mutual aid; and the creation of a healthy environment.

Following up on this framework for health promotion, another document focused specifically on mental health, for which it proposed a broader definition.[4] By defining mental health as the capacity of the individual, the group, and the environment to interact effectively with one another, it is possible to differentiate between the concept of mental disorders (or mental illness) and

problems of mental health, which are generally less serious but much more widespread.

The document acknowledged that, "in many instances, we still lack the knowledge to say which mental health problems have a mental disorder component and which do not." The real merit of the document, however, was to point out that the presence or absence of mental disorders is only one of the factors affecting mental health. Finally, the document indicated several guiding principles to promote mental health, in particular mutual aid and voluntary service, participation and autonomy.

Of the studies that have helped to determine the role of mutual aid in health, many have established links between health and social support.[5] One of the first studies (and a notable one) showed that people with the strongest social relationships have mortality rates that are half those of people with the weakest social relationships. Four different types of social ties were taken into account: marriage, relationships with parents and close friends, membership in a religious group, and membership in other groups. The study was based on a sample of 7,000 persons who were monitored over a nine-year period in the county of Alameda, California.[6]

We already know that certain behaviours, such as smoking and drinking, are harmful to our health; now we know that social support has a positive effect on our health as well — just as regular physical exercise does. We have likewise learned that changing behaviour is often difficult and takes a long time. Those who have made multiple attempts to quit smoking or drinking know this well. Similarly, it is not easy for someone who has kept to himself for years to establish a small circle of friends, or for someone who has lead a largely sedentary existence to start exercising regularly.

Given these difficulties, some people think it is more realistic and effective to address the environmental problems that contribute to harmful or unhealthy behaviour. This approach seeks to change social attitudes toward smoking and to modify or introduce laws to reduce or even eliminate the use of tobacco. Reducing risk by changing the environment is an important part of health pro-

tection. At the same time, however, it is crucial for people who want assistance to have access to the best possible help in order to free themselves from unhealthy behaviours.

Changing harmful habits is therefore an important means of maintaining and improving our health. Chronic illness, which currently accounts for most serious health problems, especially among senior citizens, also calls for adjustments and changes of behaviour. Hypertension, arthritis, osteoporosis, respiratory illnesses, chronic depression and schizophrenia affect individual capabilities, as well as the daily routine of sufferers and those around them. The psychological and social difficulties that stem from such conditions are leading more and more people to seek help. Crises such as the death of a spouse, separation, and divorce affect mental health and call for changes in attitude and behaviour.

In times of crisis or illness, people have access to a range of resources that they may call upon singly or in various combinations as needed. As sources of social support, mutual aid and self-help groups are among these resources. We will examine their role in the context of the health promotion model presented below.

Person-Centred Health Promotion Model

It is not easy to give a simple definition of health. The concept of health promotion has the advantage of showing that health is not a static state that is reached once and for all. Rather, it is a dynamic process that allows a person to control, maintain or improve his or her mental and physical condition. Those concerned with public health must regularly review available resources as well as strategies and actions in light of advances in knowledge.

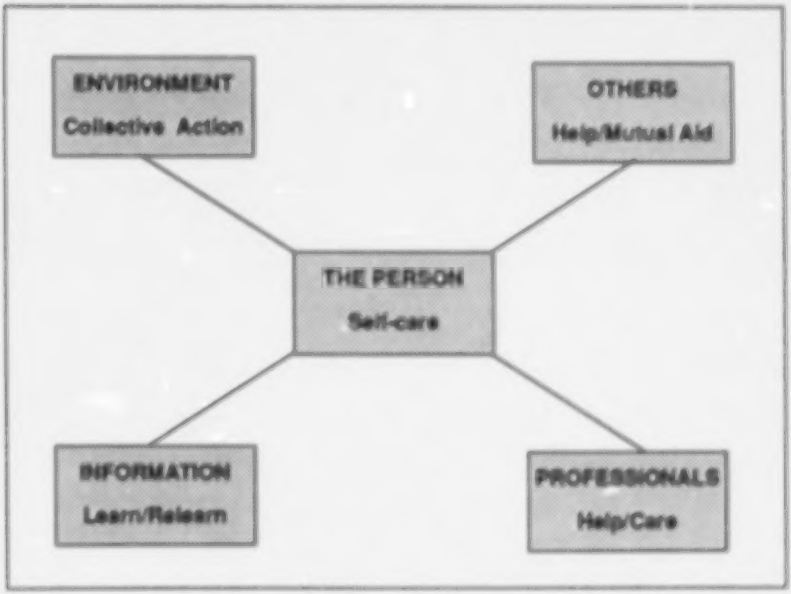
Let us examine the resources and actions that permit people to exercise more control over their own health, leaving aside interventions by health care professionals, governments, institutions, associations, or other authorities concerned with public health.

The *person-centred health promotion model*, which could also be called a "personal health model," answers the following question:

> *What resources are available to a person who is experiencing a crisis or health problem and who wants to maintain or improve his or her health?*

As shown in the accompanying diagram, the individual has five basic resources: him or herself, others, professionals, information, and the environment. The principal type of action associated with each resource is listed under the resource in question; we examine these actions later in the chapter.

Person-Centred Health Promotion Model



The Person: Self-Care

When dealing with a crisis or health problem, we can turn first to our personal resources; after all, the problem concerns ourselves as **persons**, with our own experience and capabilities, self-knowledge, and understanding about our own health and health in general.

Self-care means taking care of our own health and acting autonomously; it also means calling upon our own resources in making decisions and taking action to monitor and improve our current and future health.

Autonomy must not be confused here with independence. It is now well established that our health and well-being depend to a large degree on others — on our human environment — and that we therefore live in a state of fundamental interdependence. We must recognize and accept the limits of our personal capabilities and knowledge so that we can use help and mutual aid wisely, or acquire new knowledge that challenges our assumptions about ourselves and our health.

Self-care, or assuming responsibility for one's health, therefore implies a set of attitudes, behaviours and actions, such as avoiding excesses, being patient, taking appropriate measures to avoid risks, avoiding various forms of dependency, being attentive to others and to our environment, listening to our bodies, developing self-understanding and, above all, knowing how to evolve at our own pace.

Self-care can take different forms, depending on the person's condition and stage of development. We do not expect a small child, an adult, and a senior citizen who has become blind to exercise their autonomy in the same way. However, we often underestimate seniors' capacity for autonomy, and some parents never learn to recognize their children's capacity for autonomy.

On the other hand, some people may lose their desire to live and consequently to improve their health. For these people, the concept of self-care is virtually meaningless.

Others: Help and Mutual Aid

Others are defined as those with whom we have already established relationships or significant bonds and who are therefore possible sources of help. They constitute our human environment and include parents, friends, colleagues, neighbours, members of our community, and members of various organizations, associations and groups, such as self-help groups. Professionals may be included in this category as long as they do not act as professional helpers.

We can obtain different types of *help* from these different human resources which constitute our social environment in its broadest sense. This help has been called *natural help*[7,8] to distinguish it from professional help; some authors, however, prefer the term social support.[9,10]

Guay identifies four main sources of natural help: a personal social network, neighbours, self-help groups and volunteers.[11] *Mutual aid* is therefore a specific type of social support or natural help. In the model presented here, we distinguish between the two major categories of helpers: professionals and others (or non-professionals), including self-help groups.

Volunteer help can be offered spontaneously — often individually, as when we offer to help a neighbour — or it can take an organized form, as in various groups and organizations. The same is true for mutual aid, with self-help groups constituting the main type of organized mutual aid. In mutual aid the person receiving help plays an active role, whereas the role of the person being helped by a volunteer is often passive.

Professionals: Help and Care

When they are ill, most people usually think of seeking professional help. **Professionals** here include doctors, nurses, many types of therapists practising inside and outside the health care system and its institutions, psychologists, social workers and other professionals working in the field of human services.

Two types of circumstances may prompt someone to seek *help*

or *care*. In the first, the individual sees a doctor or other health professional to be treated or cared for, without explicitly seeking help of a psycho-social nature, although such help may be forthcoming during the visit. In the second case, the individual visits a professional in health or human services specifically to obtain help for a social or psychological problem arising from personal or emotional difficulties or relationships with others. Psychological care, counselling, advice or treatment is the result.

Information: Learning and Relearning

The **information** in question is information on health, life crises or illness. Information can be obtained from books, magazines, brochures, periodicals, tapes, and numerous other types of published material. Other sources include courses, workshops, information sessions, and training of various kinds. People who become chronically ill or go through a crisis often have difficulty finding information about their situation and needs. A range of medical information may be available, but information that uses simple language to convey both scientific and clinical knowledge and the experiences of those who have suffered crises and chronic illness appears to best meet public needs. It also requires further development.

When it comes to taking responsibility for our own health, information is generally useful only if it helps us to change our behaviour or attitudes. We have to *learn* or *relearn* in order to maintain or improve our health — in other words, to educate and re-educate ourselves. This learning process is not accomplished simply by reading a book, listening to a tape, or watching a film. Learning often requires us to talk to others and discuss the issues in workshops, courses, seminars, or training sessions. Such exchanges may take place between members of the same group, or between participants in a group and the leaders, instructors or speakers, who are often professionals. This last point illustrates the interdependence of the five resources identified in our model. Influence and advice from friends and acquaintances often play key roles in our decision to read an article or book or take a course.

Similarly, it is often on the advice of parents or friends that we decide to consult a given professional.

As we saw in Chapter 2, certain self-help groups are a source of health education and information. Many organizations such as community centres and teaching institutions in the public, private and voluntary sectors offer similar services. Finally, it is the responsibility of all professionals working in health care and human services to encourage us and help motivate us to find the information and learning environment appropriate to our situation.

The Environment: Collective Action

The **environment** is a vast and multi-faceted health resource. In a sense, the environment is everything outside the person, including the social, physical, economic and work environments. However, we have excluded two categories — professionals and others. The environment, which has the potential both to foster and to threaten good health, therefore includes not only the quality of the air we breathe and the water we drink, but also such factors as our working conditions, the level of unemployment, and the nature of health and social services in our community.

One person acting alone can make only very limited changes to the environment, because such changes generally require *collective action*. Many health problems can be attributed largely to the environment and to our own behaviour. Thus harmful stress, which can result from excessive environmental pressures (unemployment, unhealthy working conditions, etc.) can be defined as an unmanageable discrepancy between the constraints and pressures of our environment and our capabilities, as determined by our biological makeup, our habits, our lifestyle, and so on.

In the case of a stressful work environment, the solution may lie in modifying certain habits, using relaxation techniques or, if possible, changing jobs. Generally speaking, however, such situations call for collective action to change the environment.

People facing a crisis or the aftermath of upheaval are usually so vulnerable that they may not have the energy to get involved in collective action. In addition, they naturally tend to seek an

immediate solution to their problems. For example, drug addicts who want to kick their habit may show no interest at all in actions to eliminate a drug ring.

After they have received support from a mutual aid or self-help group, however, many people are willing to become involved in community or social action, to help change certain aspects of their social structure, set up new programs or services, fight for new laws or changes in legislation, lobby for more research, or raise money for their cause.

Personal Health and Self-Help Groups

Our health promotion model allows us to formulate a new concept of health by defining it as the art of making the best possible use of our five basic resources (oneself, the environment, others, professionals, and information). And we have emphasized the importance of the person and his or her own resources, thus enabling us to define self-care as a set of actions and underlying attitudes that draw upon our personal capacities.

Under certain exceptional circumstances (for instance, if you get lost on a wilderness hike), self-care is the only possible answer. In everyday life, however, most people can generally depend on at least several of the five resources in our model.

We can therefore propose a second and broader definition of self-care:

> *Self-care is the art of acting, for oneself and by oneself, on decisions regarding which of the five basic resources to use.*

This new definition of self-care leads us to the concept of personal health. It is a dynamic concept of health, because human beings live in a state of constant change.

According to this definition, self-care is the process of making the best possible use of the five resources identified in the model. That description covers the means, but we have yet to clarify the ends.

These ends can be defined in terms of the five basic human

needs: physiological, security, love and a sense of belonging, esteem, and self-actualization.

On that basis, we can define personal health, at least in indirect terms:

> *Maintaining or improving one's personal health consists of using the five resources — oneself, others, professionals, information and the environment — most effectively in order to satisfy the five basic human needs as fully as possible.*

This definition enables us to understand the relationship between self-help groups and personal health. Self-help groups contribute in particular to satisfying three basic needs: security, love and a sense of belonging, and self-esteem. We still need to examine the degree to which these groups encourage the use of the five types of resources to promote personal health.

Self-help groups encourage the use of others' help through the practice of personal mutual aid, and they often lead to or stimulate collective action to correct unhealthy aspects of the environment. A good example is the group of mothers whose children had been killed by drunk drivers; they decided to take collective action against drunk driving to prevent future accidents.

The vast majority of self-help groups call upon three resources: mutual aid, of course; regaining control of one's life by drawing on the individual's personal strengths; and, information and learning. A large number of self-help groups also engage in social action.

Where the use of the fifth resource, professional help, is concerned, self-help groups hold differing opinions. Some groups have little interest in professional help, believing that it should be up to individual members to decide whether to use the services of a professional. Other groups reject the idea of professional help for various reasons, most of which stem from negative experiences in the past. Groups in a third category work very closely with professionals. This is particularly true of people who have undergone major surgery, such as open heart surgery, cancer operations, laryngectomies, and colostomies. More than two million people worldwide had had colostomies as of 1980, for example. Members of these and similar groups have literally gained a new lease on

life thanks to modern medicine.[12] But survival brings its own challenges; these people are our new disabled, and their top priorities include personal adjustment and social reintegration.

We have seen that self-help groups emphasize autonomy, both for themselves as organizations and for their members whose aim is to take charge of their own lives. Self-care, which emphasizes drawing on one's own resources, might seem to contradict mutual aid, which puts the emphasis on seeking help from others. The contradiction is more apparent than real, however; this becomes clear when we examine the broader definition of self-care. Self-care is not so much *acting* for ourselves by ourselves, but above all *deciding* for ourselves by ourselves. This means deciding what to do and where to turn. In many situations, given the nature of some difficulties and illnesses, the decision to join a self-help group may be the best one. It is the help available from a self-help group that enables us to gain or regain control over our lives and develop the capacities necessary for self-care or personal health. This capacity in turn enables us to draw upon all available resources, including professional help, diverse sources of information and learning, and participation in collective or social action.

Self-help groups are a particularly powerful means of maintaining or improving personal health, and through them self-helpers can gain access to new or renewed personal control over their own health. In our view, the definition of personal health must extend beyond the person, for a human being cannot be considered in isolation. Each must be recognized as an autonomous entity interacting with others and with the environment.

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6

Seeking Help and Joining a Self-Help Group

This chapter begins with a description of the various sources of help and the conditions necessary for obtaining it. Sometimes attitudes prevent us from getting the help we need. These attitudes are described in the second section, which deals with the myth of independence, and in the third section, which identifies several principles underlying the art of asking for help. The fourth section presents a hypothetical case of one person's attempts to find solutions, his reflections before joining a self-help group, and his first experiences in the group. The final section shows how some groups succeed in helping even those people who are extremely reluctant to join a group and explains the role of humility and anonymity in this success.

Help or Mutual Aid: The Choices Available

In Chapter 3 we saw the main characteristics of mutual aid (common experience, help freely given, and equality) as one form of help. Let us now take a closer look at the various sources of natural (or non-professional) and professional help, and at the different forms help can take. This will give us a better understanding of the resources available to someone seeking help.

There are three main sources of natural help and mutual aid.

First we can turn to our immediate circle of family and friends. Just beyond this lies our social environment, a less intimate circle that includes acquaintances, neighbours, colleagues, and everyone with whom we have fairly regular contact or whom we have come to know through membership in a group or association.

Finally, there is a third level: we can seek help or mutual aid from people we have never met before, but who belong to groups and voluntary organizations set up specifically to help people experiencing difficulties.

Natural help, or social support, takes many forms. Gottlieb, a Canadian researcher, has reviewed studies in this field and identified twenty-six different helping behaviours, which he divided into four categories.[1] Of these four categories, the two most important are emotional support and problem-solving behaviour. Giving emotional support includes reassuring, encouraging, listening, understanding, showing concern and trust. Helping someone solve problems is a more active behaviour and includes providing clarification, suggestions, directives, information, material aid and distraction from problems. One merit of these studies on social support is that they make us aware of the extraordinary diversity of help. In other words, if one form of help does not work for us, there are undoubtedly other forms that will.

However, what we term "helping behaviour" is in fact a theoretical concept; the same behaviour can have entirely different effects depending on the circumstances and the helper. In addition, the attitudes of the helpee and the helper toward each other are crucial.

Indeed, a fundamental prerequisite for helping, and one that is too often ignored, is that the person in need of help *must feel comfortable* with the helper. Thus it may be very effective to talk to a trusted friend if one feels understood by him, but much less useful to talk with a relative, if he is lacking in understanding. Talking with one's boss can be harmful if one feels both misunderstood and prejudged.

For assistance to be effective, therefore, two conditions must exist:

- the helpee must feel understood; and,
- the helpee must feel accepted, not judged.

These two conditions are fully met through mutual aid. Because of its first characteristic (common experience), the helpee feels understood, and thanks to the third characteristic of mutual aid (equality), both helpee and helper accept each other as equals.

There are two different instances in which people seek help from psycho-social professionals. In the first instance a person may suffer from a mental illness, or a crisis may trigger a mental disorder. Such difficulties call for the specialized techniques available through psychiatry and psychotherapy. In the second and far more frequent situation, people experience a crisis or illness which to some degree affects their mental health, usually with no detectable sign of mental illness or disorder. In this second case, informal help or mutual aid, and especially some self-help groups, can be appropriate options, provided they are available.

Thus a broad spectrum of choices and different forms of help are available, including immediate family, friends, and professionals. Self-help groups must be counted in as well. Recent increases in their number and diversity indicates that they fulfil significant needs for many Canadians.

Although help is widely available, some people hesitate to reach out for it, even if they need it desperately. Let us explore the sources of this reluctance.

The Myth of Autonomy

What we refer to as the myth of autonomy is the belief held by an individual who has unlimited confidence in his or her own capacities, who relies on himself or herself alone, believing that others cannot be relied upon and that it is therefore better not to open up to them. This fallacy is not true autonomy, but simply independence pursued at any cost. People in trouble may often have

particular attitudes that make the myth of autonomy difficult to dispel.

Weakness

The first attitude is that seeking help is a sign of weakness. Such an attitude, which may come from family, school, or the broader social environment, is a misconception that often takes a long time to correct. It is often a struggle to accept the fact that we are not capable of overcoming all our difficulties alone and to show both humility and courage by seeking help.

Uselessness

The second attitude is that seeking help is useless. This may result from a series of unhappy experiences where someone either did not find the right help when needed, was rejected, found that the help offered was useless or even harmful, or simply did not know how to ask for the necessary help.

Indebtedness

The third attitude that prevents people from seeking help is that we become indebted to others when we do so. In social relationships, and even with family and friends, it is true that there are quite often expectations of reciprocity. It follows that in most situations we owe something to the helping person or organization.

In the case of mutual aid, however, we have seen that self-helpers gain a wide range of benefits from the help they give, and that the immediate satisfaction they gain eliminates any desire to be paid back. This is what we have described as the magic of self-help. Someone who is afraid of becoming indebted is obviously unaware of this aspect of mutual aid, never having experienced its give and take or never having been aware of it.

The person who is afraid of being indebted to others believes in the simplistic principle that if you receive something, you somehow have to give something in return. This type of person tends to favour paid professional help, if it is available and affordable.

The problem of indebtedness is overcome by paying for the service directly or through insurance.

In a recent study, the myth of autonomy or, in its exaggerated form, super-autonomy, was identified as a possible factor in suicide attempts by junior college students.[2]

The myth of independence thus appears to be the source of many people's reluctance to seek help, even when they face serious difficulties. Nevertheless a certain number do decide eventually to swallow their pride and ask for help or join a self-help group. What happens to bring about this change?

Social Courage

Rollo May, an American psychotherapist and author, answers this question in a book entitled *The Courage to Create*.[3] It takes what he calls social courage — the courage to establish bonds with other human beings and to risk opening up to another in the hope of achieving intimacy. For someone convinced that he or she does not need others, proudly claiming to be totally independent, it does take a lot of courage to reveal personal difficulties or suffering to someone else. This is social courage. (Rollo May distinguishes four kinds of courage: physical courage, moral courage, social courage and the courage to create.)

According to May, social courage requires us to face certain fears, such as being absorbed or taken over by someone else, the loss of independence or autonomy, and the loss of identity to the other. These fears are the kind associated with the myth of autonomy, a myth that is particularly common among men.

How does it happen, then, that people find the courage to face their fears and open up to others? It results largely from personal growth and is the result of an individual's decision. Certain situations, however, strengthen people's capacity for social courage. One of the great merits of self-help groups is that they are able to create situations that make it easier for people to open up and to display social courage among others who have experienced similar suffering.

Social courage has two components. The first is the act of overcoming resistance, which shows up as negative attitudes. The second is taking action and seeking help. But even then, we need to know how to ask for help.

The Art of Asking for Help

Someone wanting to seek help may experience various emotional blocks. The person may be afraid of getting no for an answer, of being misunderstood, or of even being rejected. Knowing how to ask for help is an art most of us have never been taught, or have learned imperfectly. To learn this art, or relearn it, two principles are helpful.

Accepting Unavailability

When we need help, we consciously or subconsciously consider a variety of options, including friends, relatives, acquaintances, and organizations. If we contact a friend who tells us directly or implicitly that he or she is not available or offers minimal help that does not meet our expectations, chances are that we will react badly. In fact, we often interpret this response as rejection, instead of accepting that the person is simply not available. Yet the friend may have a perfectly valid reason. Without our knowing it, the friend may be under considerable pressure, preventing him or her from responding to our difficulties. Perhaps our troubles touch a sore point in others and awaken conscious or unconscious fears that are difficult to face. People suffering from incurable or terminal illness, particularly AIDS, unfortunately experience such negative reactions on the part of friends and relatives. By turning to a self-help group or a voluntary organization, however, we are certain to find helpers who are available.

The way we request help also affects people's willingness to become involved. If the person looking for help lists all his or her problems, or wants to rely too much on the helper, the potential helper may feel overwhelmed and refuse to get involved. Sometimes the sufferer gets this way because he or she has waited too

long before seeking help. This leads us to the second key point in the art of asking for help.

Recognizing our Need for Help in Time

An important factor in obtaining help is to avoid waiting until one is caught up in a crisis of overwhelming proportions. With practice and vigilance, it is possible, though not always easy, to predict impending crises. Many crises, serious problems, and "accidents" are preceded by warning signals that have been ignored: slight memory losses, physical pains, insomnia, etc. These are often symptoms of stress caused by problems related to work, family, or one's social environment. As readers will recall, one element of self-care described in the previous chapter was the ability to listen to one's body.

Joining a Self-Help Group

We have seen the advantages of mutual aid and self-help groups compared with other forms of natural help. Even so, people who might consider it natural to seek help from relatives, friends and neighbours may feel intimidated by the thought of joining a self-help group made up of strangers.

The natural tendency of people seeking non-professional help is to turn to someone they already know. Every crisis and chronic problem raises fears, especially a fear of the unknown. When seeking help and comfort, we naturally turn to familiar faces.

In relatively common situations, such as separation, divorce or the death of a spouse, it may be possible to find someone in our own circle who has gone through similar difficulties and with whom we can establish a fruitful relationship.

The more unusual the difficulty, however, the harder it is to find someone close by who has experienced the same problem. This is one of the most significant advantages of self-help groups.

What does a person generally experience just before joining a self-help group and during his or her first contacts with the group? Consider the hypothetical case of a man named Peter, whose life

has been overwhelmed by a sudden crisis or by a habit he cannot kick and that is ruining his life.

Peter thinks of the sources of help he could try. He considers several family members, then a few friends who live reasonably close by. Unfortunately, some of these people are away, while others are not available.

Peter then thinks of a priest he knows slightly, while wondering whether he should consult his doctor, a psychologist, or some other therapist. For various reasons, he rejects these approaches, fearing the professionals will not understand him well enough. He thinks of leisure activities he could take up and clubs he could join. On reflection, he decides that none of these possibilities suits his needs.

Peter feels very much alone with his problems and the emotions that repeatedly overwhelm him; he seems to have no one to whom he can confide his troubles and still feel accepted. Then he learns of the existence of a group of people in the same situation as he is. In this group, some have already overcome crises or have learned to cope with chronic problems, while the majority are still struggling with their difficulties.

The dozen or so members of the group meet once a week. Nonmembers can go to several meetings before deciding to join. Peter decides to go to a meeting to find out if the group can be of help to him. Although not entirely at ease initially, he is drawn to the atmosphere of human warmth and understanding that seems to prevail. He therefore returns to subsequent meetings.

During these initial meetings, Peter listens, discovering how much the situations, reactions, attitudes, fears, and emotions of the others resemble his own. He feels a little less alone in dealing with his difficulties; some of the problems others are experiencing seem greater than his own. He feels somewhat relieved and rediscovers his ability to "pull up his socks." The collective experience of the group shows him how to overcome one difficulty or another; the knowledge may be useful to him later on when he is on the verge of giving up, convinced that he will never make it.

Then one day Peter decides to relate his difficulties, fears and

hopes to some group members or to the group as a whole. No doubt it takes a great deal of courage to talk about acts or feelings he is still ashamed of. Having decided to do it, however, he is astonished at the understanding and acceptance offered by the other group members. He experiences the intensely liberating feeling of becoming more accepting of himself, less isolated, and closer to others.

Paradoxically, in the very process of learning to better accept his strengths and weaknesses, Peter discovers the energy necessary to make some changes in his life and to become stronger as a result. At the end of a meeting during which Peter speaks, a member comes over to tell him how much his remarks moved him and how close he felt to him at that moment. It is now Peter's turn to experience the satisfaction of finding that his participation has touched and helped another member of the group. Peter realizes the full effect of the mutual aid being practised in the group and feels the satisfaction that comes from giving and receiving at the same time.

Peter's experience with a self-help group is typical of many members. There are other ways to join self-help groups, however.

Many people are in no condition to attend meetings or they resist the very idea of being in a group, preferring one-on-one relationships. Recognizing these difficulties, some groups offer personal visits or home visits that continue until the person is ready to come to meetings. Other groups, such as some for widows, base their activities on one-on-one sponsorship arrangements.

Equality, Humility and Anonymity

In Chapter 3 we saw that the feeling of equality is a characteristic of mutual aid and that it is self-reinforcing when combined with the common experience of self-help group members. Often the mutual aid experienced in a group is what enables a new member to feel equal to the other members. The experiences of mutual aid and equality reinforce one another: the more equal group members feel, the more they engage in mutual aid, and the more they practise mutual aid, the more equal they feel.

It follows that someone with strong feelings of inferiority or superiority will have trouble becoming part of a self-help group. These types of feelings can be traced back to negative childhood experiences associated with faulty attitudes or upbringing. Some self-help groups, however, do manage to accommodate such people, as we will show.

The tendency to consider oneself superior to others is a form of pride associated with the myth of autonomy. This attitude is often found among alcoholics. As Christian L., a member of Alcoholics Anonymous, stated, alcoholism for him is an illness of false pride.

Indeed the challenge is considerable for alcoholics who want to stop drinking but cannot, and whose lives have been shaped by their belief in the myth of autonomy. On one hand they do not want help, because it runs directly counter to their beliefs; on the other, they know they need help because they fall victim to their own behaviour and are forced to recognize that their own efforts have failed.

By drawing on the sense of self-worth that comes from practising a form of mutual aid based on spiritual principles, Alcoholics Anonymous has found a formula that has proved effective for many alcoholics. By turning to a power greater than themselves for assistance in regaining a healthy lifestyle, AA self-helpers see themselves as intermediaries and do not claim the healing power as their own. This attitude fosters a sense of humility and counteracts any tendency to feel false pride.

The concept of anonymity also plays a major role and is adopted by many groups besides AA. On a personal level, anonymity protects the individual from public exposure as an alcoholic or as a member of any other stigmatized group — especially important to relationships in general. Anonymity also preserves the equality of all members by preventing media coverage and thwarting those who would be tempted to take advantage of their situation for prestige or personal gain. Humility, practised individually and in groups, is one of the most important elements in rehabilitating alcoholics who suffer from false pride. "What's

bred in the bone comes out in the flesh," says the old proverb. The principle of anonymity is adopted precisely to avoid this risk.

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7

Evaluating Self-Help Groups

by Francine Lavoie

It is vital to examine the effectiveness of self-help groups because self-helpers and society at large must be aware of their advantages and limitations. There is little point in planning social policies or interventions on the basis of false premises.

This need for critical analysis of self-help groups is tempered by the difficulties inherent in carrying out any evaluation — difficulties in agreeing on evaluation methods or the content to be evaluated, and the danger of neglecting essential components of the phenomenon under study. In addition, the political context in which such evaluations are conducted cannot be ignored. Audrey McLaughlin describes the work done by Yukon native women in setting up transition houses for battered women and former women prisoners, noting that these new services have to meet uncommonly rigorous evaluation requirements:

> "They are evaluated and scrutinized with an assiduousness that one could only wish was occasionally applied to major established services. The continuous need to rationalize the service, while not entirely without merit, leads one to believe that this reflects less a felt need to protect the taxpayer and

a more generalized feeling that there is still something not quite deserving about services for women."[1]

It is possible that self-help groups, especially if they are financed through the health or social services system, are also subjected to this type of pressure. In this chapter, however, we examine evaluation studies conducted to increase knowledge, not for purposes of monitoring groups that receive funds.

Evaluation here means judging the quality of a service. Common evaluation methods include "process analysis" (helping activities and mechanisms) and impact studies (benefits or disadvantages to the participants). After presenting a classification of self-help groups to provide reference points for evaluation findings, we pursue the following questions: 1) What happens in a self-help group? In other words, what are the activities, the helping factors, the ideologies? and 2) How effective are self-help groups and, more specifically, what is their impact on members, and are they organizationally effective?

We distinguish six types of self-help groups, corresponding to six categories of problems for which people look beyond the help available from specialists or from their family or social circle: 1) addiction problems; 2) long-term psychological problems (violence, phobias, depression, etc.); 3) life crises (death, birth of a handicapped child, etc.); 4) chronic physical illnesses; 5) difficulties experienced by a family member; and 6) problems of identity or social rejection (such as those experienced by gays, or by women).[2]

Let us look now at the first evaluation question.

What Happens in a Self-Help Group?

Given that many self-help groups are relatively recent, researchers have tended to rely on methods developed to study the effectiveness of various forms of psychotherapy or group therapy. Thus, they are interested in whether the helping factors identifiable in therapies are present in the self-help groups, and what values self-help groups advocate. First, however, researchers need to be-

come familiar with the day-to-day workings of the groups. Research studies fall into three categories: those relating to 1) activities; 2) helping factors; and 3) ideologies.

Activities

Group meetings and the sponsorship of new members by more senior members are considered the most typical activities of self-help groups. As a 1982 Canadian study showed, the most important activities to the groups studied, and to which these groups gave most attention, were activities that fostered personal sharing, that is, group meetings and sponsorship.[3] The next priorities for these groups were educational activities for their members and the general public, and advocating for change.

Apart from these general services, the activities are as diverse as the groups themselves. They include home or hospital visits to the sufferer, hot lines, newsletters and brochures, public conferences, fairs, advocacy, recreational activities, and material aid (sitter services, transportation, exchange of goods, etc.).

Services can be offered in more or less formal ways, such as accompanying someone during legal proceedings, offering a friendly presence to someone experiencing a late-night crisis, establishing a databank of resources, and so on. Providing such services sometimes assumes an important role, often to the detriment of the helping process within the group. A study of 156 groups affiliated with an American association, the National Alliance for the Mentally Ill, showed that more than a third were involved in promoting new programs for their children who suffered from mental disorders, especially programs involving housing, integration in the workplace, and recreation. Many members believed that such undertakings were distracting the groups from their self-help activities.[4]

Preferred methods of communication within a group may be influenced by the type of difficulty that led to the formation of the group, but also by other factors, such as the number of people involved or the geographical distance between them. Organizations that emphasize meetings are often located in major urban

centres. In rural areas, the telephone may become a more important tool than group meetings. In the case of very rare problems or diseases, a newsletter can reach a more thinly scattered membership. For example, the newsletter of the Quebec association for people with celiac disease reaches about 800 people across the province who are allergic to gluten, a relatively rare condition that necessitates major changes in diet. Networks of home computers also enable people in different regions to communicate with one another according to a predetermined schedule. In Montreal, the *Presence* project confirmed that this means of communication is highly appreciated and often allows isolated people to take their first step toward others. Disabled persons, victims of sexual abuse, seniors, and AIDS sufferers participated in these early experiments.[5]

The activities just described are not practised by all self-help groups because a group's predominant activities generally vary with the nature of the problem shared by the members. For instance, sponsorship seems to work particularly well for people having trouble facing a group of peers, as they must first acknowledge that they share the same condition. Experience has shown that difficulties arising from a blow to one's social identity (loss of a spouse or job) or one's body self-image (removal of a breast) lend themselves well to a sponsorship relationship, since people in a state of shock may refuse to acknowledge their new condition or to associate publicly with a self-help group. In another type of situation, parents of schizophrenics, for example, may choose to invest their energies in trying to change the health system through social action rather than seeking individual solutions.

Concentrating on some activities may lead to the neglect of others. Some advocacy groups admit to having insufficient time to offer activities related to emotional support for members. Other groups that organize recreational activities are often criticized for neglecting the primary objectives of self-help. Certain groups adjust to these difficulties. Thus, MADD (Mothers Against Drunk Driving) has developed two distinct programs — one for advocacy, the other for support. Auto-Psy (a group for former psychiatric

patients) has chosen to emphasize social action and is interested specifically in human rights.

Finally, it should be mentioned that educational activities for members or the general public usually consist of calling upon professionals to speak on their area of expertise, rather than members' testimonials. For example, most of the speakers invited by groups concerned with medical problems are health professionals. Such talks may be a non-threatening way of recruiting new members, but some groups are opposed to an emphasis on specialized knowledge at the expense of members' real-life experiences. We will see later that this kind of activity even influences the type of help available within a group.

Descriptions like these give us a superficial understanding of self-helf groups, but to deepen our understanding, we must examine what members receive through self-help group activities and, in particular, what the helping factors are.

Helping Factors

Early on, researchers wanted to identify the helping factors present in self-help groups, more specifically: 1) Can we identify interactions that are considered helpful in these groups? and 2) What are the mechanisms through which help is transmitted?

Until now, this type of research has focused on small group meetings. To our knowledge, only one study has dealt with the identification of helping factors in a sponsorship relationship between two people.[6,7]

The helping factors identified will be described and we will share group members' opinions (where applicable) and researchers' remarks. Less than five per cent of the communication in the self-help groups observed consisted of chatting or idle talk, confirming that members take the meetings seriously.[8,9]

Emotional Support

Members of self-help groups often speak of the importance of emotional support. The expectation of this type of support is in fact what distinguishes active members of the Scoliosis Association

from non-members afflicted with the same disease.[10] In a survey of a number of self-help groups, American researchers discovered that 83 per cent of the members felt that the emotional support they received was what had helped them most.[11]

In a critical review of this study, one academic noted, however, that the eight groups surveyed were all of a similar type.[12] They were Alcoholics Anonymous; Overeaters Anonymous; Parents Anonymous (for parents who abuse their children); two groups from Take Off Pounds Sensibly; Emotions Anonymous; Make Today Count (for people with cancer); and Parents without Partners (for the heads of single-parent families). These groups all focus on discussing members' difficulties, are part of national organizations, are directed by their members and, apart from Parents Anonymous, exclude professionals from the role of co-leader. It may well be possible, then, according to this researcher, that other types of groups, such as those that place more emphasis on recreational activities or talks by professionals, place less emphasis on their emotional support role. Even so, the mere presence of a professional as a co-leader does not seem to diminish the sense of receiving support, particularly if members are the real leaders and professionals provide assistance only, as is the case for groups for abusive parents.[13] Still open to question is whether group members perceive diminished support where professionals play a more active role.

In a 1986 survey of organizations identifying themselves as self-help groups, a researcher found that one of the groups did not provide for an exchange of emotional support and that the evidence of other helping factors was weak as well. The group was made up of retired seniors who attended talks on subjects of general interest. The researcher concluded that the group probably was not a self-help group.[14]

There is therefore evidence of emotional support in self-help groups and, to a lesser extent, in groups whose main activity consists of conferences and discussions led by people from outside the group.

Support can take many forms. In a study of GROW groups for people with psychiatric problems, support is seen as feeling accepted and not stigmatized.[15] Another study mentions that people with cancer feel a strong need to express their feelings after bad experiences with the medical profession.[16] Other people speak of the importance of a supportive social environment. Finally, one researcher views support as having four aspects: 1) offering empathy (understanding of the problem and being at one with the particular feeling expressed by another); 2) reassuring the person that he or she is important; 3) offering hope of resolving difficulties; and 4) reassuring the person that his or her behaviour is normal.[17,18]

Meeting Fellow Sufferers

In Chapter 3 the importance of the resonance that comes from sharing a common problem and the identification it gives rise to were explained. We elaborate on this point here by examining it as a helping factor.

What are the benefits of meeting fellow sufferers? Three elements can be highlighted. First, it provides an opportunity to **measure our experience** against that of others. Many self-helpers say they realize that they are not the only ones facing the same difficulty, and they also recognize that others are sometimes in situations worse than their own. Another helping factor is the learning that takes place by **observing role models**; in this way, through association with senior members who have overcome their problems, newer members discover hope for their own difficulties. Nor should we undervalue the importance of observing others in their attempts at change or adaptation, from which much can be learned. Indeed it is recognized that we learn less from someone who has already solved a problem than from someone still trying to overcome it. In addition, such meetings provide an opportunity for members to **make new friends**.

Systematic observation of sixteen self-help groups confirms the existence of these three factors.[19] One researcher also remarked after observing groups for abusive parents that parents found it

important to know they were not the only ones facing the problem.[20]

Members themselves point out the existence of such factors. According to about 1,700 women participating in consciousness-raising groups, the possibility of comparing oneself to others is considered to be one of the main helping factors in such groups.[21]

The chance to make new friends is also mentioned in several studies. In studying self-help groups for widows and widowers, two researchers not only confirmed this as a helping factor but held it to be the most important in explaining the improved well-being of participants. Indeed, members who had only gone to meetings without creating new ties received fewer benefits than the others, even if they benefitted from other aspects of the helping process, such as the expression of emotions, comparing oneself to others, and emotional support. It seems that in the case of the death of a spouse, the possibility of creating new bonds is the most effective helping factor in self-help groups.[22]

A study of cancer patients showed that an essential benefit of self-help groups is breaking down the isolation surrounding these people, who are often rejected by those close to them.[23]

Thus these three processes (comparing oneself to others, observing role models, and creating new bonds) seem an important part of the experience of self-help groups; less is understood, however, about how they work. In addition, their effects may be stronger or weaker, depending on the problem shared by the members.

Self-Disclosure

Telling one's story, voicing one's suffering, finding the words to express it, sharing — all these elements are part of what we refer to as "self-disclosure."

This helping factor is present in all self-help groups. An American study showed that 91 per cent of the 113 GROW groups for people with psychiatric disorders used self-disclosure.[24] We also know that the numerous groups patterned on Alcoholics Anony-

mous make extensive use of self-disclosure by telling one's story to the group.

This helping factor is also used by groups for abusive parents,[25] women's groups,[26] and various other groups.[27,22] At times these testimonials are described as sharing points of view and emotional experiences rather than self-disclosure or confession, but, in any event, the participant is telling his or her story and expressing feelings to others.

According to self-help group members in a 1986 study, self-disclosure is the most typical helping factor of the self-help experience, after emotional support. Self-disclosure was almost completely absent from groups where professionals gave talks; groups that gave less time to the discussion of problems also made less use of self-disclosure.[29]

There are two types of self-disclosure: the first, personal revelation, consists of telling one's story without necessarily revealing secrets; the second, intimate revelation, consists of relating often difficult experiences that one confides to few people. Describing an attempt to say no to an ex-husband is an example of a personal revelation; admitting having been raped is an intimate revelation.

Do group sessions accommodate these two kinds of self-revelation which are both essential to the process of personal change? To answer this question, the meetings of three self-help groups were taped and systematically examined. While personal revelation was more frequent, taking up about 25 per cent of the time at meetings, intimate revelation occurred as well, taking up two to seven per cent of the time. Another conclusion of this research was that revelation often varies with the type of group. Thus, two relatively less structured groups for divorced women (Vie Nouvelle) devoted more than a quarter of their time to personal revelation and little time to intimate revelation, whereas a relatively more structured group for people with psychiatric disorders (Rétablissement, the francophone branch of Recovery) spent less time on these two activities.[30] A team of American researchers also found that groups for people with mental disorders (GROW) spent little time on intimate revelation.[31]

Self-disclosure brings to mind the possibility of expressing negative feelings toward people outside the group or toward other members. This is also one of the fears of those who criticize self-help groups. The conclusion reached after studying the three groups mentioned above (using a questionnaire on the expression of anger and aggression) was that neither the members nor the leaders perceived any such behaviour in their groups.[32] Similarly, little confrontation or punitive behaviour has been noted in other groups.[33,34,35]

Self-disclosure therefore has a place in self-help groups. It is practised in a positive atmosphere, however, thus avoiding antagonism, a characteristic that may distinguish the group experience from similar interactions with family and friends.

Clarifying Problems

One of the main merits of self-help groups is that their members can tackle one problem at a time by analyzing what precipitated the problem, discussing the consequences, and trying out solutions. Cancer patients for example experience great anxiety, feeling lost when confronted with a great number of new situations and decisions. The fact that self-help groups encourage patients to deal with just one difficulty at a time helps members feel less confused and anxious.[36]

The use of this mechanism for analyzing problems is noted both by group members and by researchers. Such a mechanism may be one of the processes that distinguish self-help groups from other forms of non-professional help, such as friends and neighbours. Some groups, especially those that are more highly structured and use a written model to guide their processes, use this mechanism more frequently. Thus, among the three groups mentioned above, the Recovery group devoted 18 per cent of the time to talk about techniques for promoting personal change, whereas the two divorce groups hardly explored this question at all.[37] The existence of this type of helping factor was noted in self-help groups that are led by peers and in groups run jointly by peers and professionals.[38]

Some people can clarify a problem for themselves simply by listening and observing others without sharing their own thoughts. Problems can also be clarified by using interpretations offered by other group members. This occurs fairly frequently in self-help groups where the discussion of personal difficulties is encouraged.[39] The process of clarifying problems can help individuals regain a sense of control in their lives by knowing where to start.

Information

Members of self-help groups receive information of various types. Comparative information helps put problems in perspective, either by situating them within a life phase or by indicating their incidence in the population at large. Thus a widow may be greatly relieved to learn that many other widows experience auditory and visual hallucinations during which they believe their husband is present. The woman understands then that it is a normal and temporary phenomenon. As for practical information, group members can find out about available services and how to gain access to them.

Information sharing occurs less frequently in the formal meetings of groups than was previously thought. Rather, information sharing tends to take place during the initial contact with the group, through unstructured contacts during or after meetings or through reading a group's printed material. However, this helping factor may be more prominent in formal group meetings that deal with medical disorders or in groups where professionals play an important role.

In summary, self-help groups offer several types of helping factors. The concept of empowerment provides a good description of what goes on in self-help groups; group members discover how to regain control of their lives and rediscover hope as well. Recent studies indicate, however, that there may be variations in the helping factors available in groups. Three variables in particular seem to influence this situation — the level of professional involvement,[40] the objective of the group (personal change or adaptation),[41,42] and the group's structure.[43] What remains, then, is to

define the optimal context for enabling the emergence and availability of various helping processes, as well as their adaptation to particular situations or challenges.

Describing activities and helping factors in self-help groups gives a limited picture of what these groups are, but neglects, for instance, characteristics such as knowledge or wisdom — in other words, their ideology. The next section therefore focuses on self-help groups' ideologies.[44]

Ideologies

"Each [self-help group] claims a certain wisdom concerning the problem it treats. Each has a specialized system of 'teachings' that members venerate as the secret of recovery."[45]

Many members and leaders of self-help groups emphasize that the mutual aid movement does not exist to offer new services or activities, but rather to advocate a new philosophy. According to these self-helpers, many self-help groups share certain philosophical or ideological ideals, a fact that does not prevent the groups from having their own specific ideologies to respond to the difficulties experienced by their members.

Too few studies have tried to analyze the ideologies of specific groups. This makes one researcher's attempt to determine the ideologies of three groups — Alcoholics Anonymous, Recovery (for people with nervous disorders) and Synanon (for drug addicts) — all the more interesting.[46] The researcher examined the beliefs on which the groups are founded — beliefs that are assimilated progressively by members and that enable members to interpret their difficulties. The researcher speaks of indoctrination or conversion, for the more intense and serious the problem is, the stronger a member's conversion to the system of belief may be. Thus the researcher believes that there is good reason for AA to claim that alcoholism is an incurable illness, that the process of change can begin only after the alcoholic has hit rock bottom, and that only then will the alcoholic admit to having no control over alcohol. As Antze explains, one of the personality traits of alcoholics is their tendency to believe they have complete control over their lives.

AA's ideology serves as an antidote to that belief; AA members learn that they do have limits but can also acquire the wisdom to accept that fact. With respect to heroin addicts, Antze points out that Synanon's approach, based on intense confrontation and the expression of feelings, compels addicts to examine their tendency toward emotional detachment and social withdrawal in the face of stressful situations.

It is possible for each group to adopt its own style of help after analyzing the particular type of problem shared by its members. These differences make it difficult and even impossible to apply the approach of a group like AA to other situations, unless the type of difficulty has some similarity, as in the case of compulsive gambling.

Further research into group ideologies would be valuable. Such research could generate greater respect for the distinctiveness of self-help groups and could help guard against excessive standardization or professionalization. Because ideology is at the heart of self-help groups, these groups are probably in a better position to encourage such studies. A study by the Regroupement des Ressources alternatives en Santé mentale du Québec (the Group for Alternative Mental Health Resources of Quebec), which examined six organizations (two of which offered self-help services), was a step in this direction.[47]

After having examined activities, helping factors and ideologies, one topic remains — the **effectiveness** of self-help groups.

How Effective are Self-Help Groups?

The question of effectiveness is crucial. If self-help groups did not contribute to improving the quality of life for individuals or communities, there would be little value in promoting their development. Our examination of the effectiveness of self-help groups comprises two parts: first, a brief review of studies concerning the impact on members; secondly, some observations about the organizational effectiveness of groups.

Impact on Members

Research aimed at evaluating impact or outcomes is difficult to conduct in the case of self-help groups, particularly using the traditional experimental approach (random distribution of participants in the group studied and in a control group, and so on). Self-help groups have values and styles of operation that do not lend themselves to the traditional methods used, for instance, to evaluate various forms of psychotherapy or drug treatment. Evaluation is further impeded by factors such as non-existent files, anonymity, variable participation in a group, and use of other helping sources while in a self-help group.

At the same time, self-help groups themselves do not attach much importance to research; not all see its usefulness, convinced as they are of the effectiveness of their services. In addition they believe, often with good reason, that the success criteria used in these studies do not take the groups' own criteria into account. The result is a disparity between the perceptions of group members and those of researchers, resulting in study conclusions that do not necessarily reflect group experience.[48] Two tentative solutions have been tried: 1) the experimental study of groups set up specifically for research purposes and modeled after self-help groups; and 2) the study of real self-help groups, using a more flexible methodology of a quasi-experimental nature.[49] A recent Canadian document provides a good analysis and synthesis of research studies on the subject, in particular those dealing with the impact of self-help groups.[50]

The experimental study of groups created for research purposes has shown that self-help can be effective and that it was group activities and helping factors, not the mere passage of time, that contributed to change.[51,52] This type of study does not capture the full reality of self-help groups, however, because it relies on experiments that do not incorporate all the characteristics of actual groups.

The study of real self-help groups gives a more accurate picture, as shown by a study of 71 groups of the American self-help association THEOS, for widows and widowers.[53] The researchers

studied members of the self-help groups, widows and widowers who declined to join any group, and representatives of widowed people in general. The researchers also compared the benefits of psychotherapy with those of self-help. They concluded that belonging to a self-help group reduced certain difficulties associated with widowhood, notably anxiety, psychosomatic disorders, and loss of self-esteem, well-being and a sense of being in control of one's life. For the type of people who join THEOS groups, psychotherapy was a less effective method than self-help. The most striking result was that active participation in a self-help group was positively related to an increase in benefits.

On the other hand, a study of bereaved parents showed that they gained little in terms of psychological or social well-being from participation in self-help groups.[54] The researchers believed, however, that participation may have prevented a greater deterioration of these parents' ability to function. They propose to monitor their subjects over a four-year period to gain a deeper understanding of the impact of self-help groups.

These two examples show that the study of real-life situations helps clarify our knowledge of self-help. An additional advantage of these studies is that their results can be readily generalized; they can also help identify the reasons behind the success of these groups. Thus the studies mentioned indicate the importance of a member's long-term commitment to a group, whether in acting as a helper or organizer or by meeting other members outside the group. Moreover, these studies show that simply attending group meetings is not enough.

Our observations here on the results of impact studies of self-help groups were not intended to be a review of all studies currently under way. This task remains to be done. No definitive conclusions about the impact of self-help groups should be drawn. Impact studies have just begun; those yet to be done will need to determine which people with what problems will be best served by which type of group.

Organizational Effectiveness

When the question of self-help groups and their effectiveness is brought up, organizational effectiveness is rarely mentioned. But when the role of self-help groups in providing services comes up, mention is immediately made of their marginal status, their vulnerability, or their operational and leadership problems, and all groups tend to be painted with the same brush.

We will here explore one aspect of organizational effectiveness, the question of leadership, which is the focus of considerable attention. At one time, the existence of leaders in self-help groups was denied, perhaps a reflection of the desire of self-helpers to create egalitarian group structures. Now experience has shown that there are various types of leadership. Whereas certain leadership styles foster the full and healthy development of groups, their members, and their leaders, other styles can fatally weaken the group, bring social recognition to the group at the expense of members' well-being, and occasionally lead to severe stress on the leader and concomitant repercussions in his or her family life. In addition, an insecure leader may try to adopt the approaches used by professionals, thus denying the uniqueness of self-help groups. Unfortunately, evaluative research has barely touched this sensitive issue, and there is even a danger that such research might ignore the unique character of self-help groups.[55]

Self-help groups encounter other difficulties, particularly the problem of persuading their members to become involved in the group and in mutual aid. We know that in certain organizations between 25 and 33 per cent of members in good standing do not go to a single meeting during the year, even though active participation is thought to be the key element in enabling members to effect change in their lives, at least in the case of certain problems.[56,57] This is another aspect of self-help groups that warrants further study.

Self-help groups often face difficulties comparable to those experienced by organizations providing traditional services. Promoting self-help groups solely on the basis of their organizational functioning would therefore be wrong. Ignoring them for the same

reason, however, would stifle the emergence of a new kind of leadership in our society.

Conclusion

Self-help groups play a useful role in our society. They contribute to the well-being of their members by offering them services that are likely to help them resolve their difficulties to some degree. They convey a message of hope and compassion that over-specialized and over-worked organizations and institutions seem less and less capable of offering. And self-help groups may well be the seedbed of a new kind of leadership.

Research has given us knowledge and insight into the unique nature of self-help groups, a uniqueness that distinguishes them from psychotherapy and group therapy. By discovering what brings about personal change in self-help group members, research allows groups to identify the need for improvements and the possible means of achieving them. At the same time, self-help groups vary considerably, and we should avoid drawing hasty conclusions and generalizing them to all self-help groups. An interesting line of research would be to pursue these studies with the collaboration of numerous self-help groups. Finally, because self-help groups complement existing traditional resources, it will be important to study further the relationship between self-help groups and human services professionals.[58,59,60]

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8

The Self-Help Movement in North America

by Hector Balthazar

My involvement in the self-help/mutual aid movement* started in 1980 while I was working in the Department of National Health and Welfare. A new position dealing with the field of social integration was created in the Social Services Division. The question of social integration, especially as it touched the mentally ill, motivated me to apply for the position, and I was successful.

This was the period when a considerable number of the mentally ill were out in the community, having gone through the deinstitutionalization process and finding living in the community very difficult. My practicum in a mental hospital as a social work student and my years of work in a psychotherapy clinic in London, England, had sensitized me to the plight of the mentally ill. These patients constituted a pathetic group in society, not only because

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* The term "self-help movement" or simply "self-help" refers to the activities of a variety of groups that are most often called self-help groups, but are also referred to as mutual aid, mutual help or mutual support groups or organizations. We also use the term "self-helpers" to designate members of self-help groups.

they were vulnerable, but also because they were stigmatized by society. The new position at Health and Welfare offered opportunities to do something for their betterment.

The field of social integration in itself is so vast that I had to explore the best way to get at it; at the outset, the task seemed quite overwhelming. I reviewed existing forms and programs of social integration in Canada and completed my research by visiting various centres. To my great surprise I discovered that many social integration activities were being provided by self-help groups, and many of these were crying out for support.

The aim of this chapter is to review, from a national perspective, some recent efforts to support the self-help movement in Canada. What has been done at the provincial and local levels, except for self-help clearinghouses, is not reported here. On the other hand, some of the work done in the United States is described, particularly in the clearinghouse section. Indeed, the sum of what has been done in the United States during the last twelve to fifteen years has been a major source of inspiration for Canadian initiatives.

The First Canadian National Meeting

As a start in 1982, a national meeting was organized comprising Canadian government officials and academics known for their writing, research or teaching in the area of self-help/mutual aid. In addition, members of self-help groups were invited from the Ottawa, Montreal and Toronto areas. Dr. Leonard Borman of the Chicago Self-Help Center at Evanston was invited as a special guest. He would act as a resource, responding to questions and concerns the Canadian group might have. Leonard Borman has since died, and his passing has been felt throughout the self-help community in North America. Anyone who knew Len (as he was affectionately called) was impressed by his dedication to all matters touching the self-help world.

The 1982 national meeting resulted in the launching of three main initiatives. The first was a how-to manual for self-help

groups. There was easy consensus on this item. Several requests had been received from self-helpers in many quarters asking for materials on how to start a group, how to maintain it, how to keep it on track, etc. Once under way, each draft of the manual was submitted to members of self-help groups for review. The book, titled *Helping You Helps Me*,[1] went through many printings and is still in demand.

A second activity considered a priority was the establishment of a national newsletter. Just for the asking, anyone interested in self-help/mutual aid could receive articles, calendar events, resources and news of current interest in the field. The newsletter would act as a central organ, serving as a link between the self-help centres that were emerging in a number of Canadian cities and recognizing the efforts of these developing centres. The first issue of the newsletter, christened *Initiative*, appeared in the summer of 1984; it has been produced quarterly by the Canadian Council on Social Development ever since.

The third activity thought to be appropriate in those early days of the movement in Canada was the making of a film on self-help groups to publicize the movement and educate the general public.[2] It would also show self-helpers themselves the breadth of the movement as well as some of the common problems and issues facing it. The film is punctuated by comments from American and Canadian experts who touch on important historical developments and policy questions.

Self-Help at Work

One of two interesting groups researched but not appearing in the film was a group for ex-prisoners, organized to give emotional and moral sustenance to those just released, while offering them work opportunities to hasten their social integration. It exemplified a type of experience rarely seen, rarely tried and certainly not widespread in rehabilitation programs for prisoners. To me, it was truly edifying to see men not often considered trustworthy, let alone capable of maintaining sustained relationships, come together in

service to each other in a way that would put many of us to shame in the so-called straight world.

The other was a group for agoraphobics.* This group became very familiar to me because I attended many of their meetings to allay their fears about filming. The experience merits recounting not only because it was unusual, but also to illustrate a type of activity peculiar to self-help that often brings startling results. The agoraphobia group met regularly on a Tuesday night to share information and experiences, to give each other support and to discover better ways of coping. One Tuesday night a woman came in late, quite out of breath. She offered apologies and gave the reason why she was late; her car had broken down and she had had to take a bus. She added that she was petrified, as she had not been on a bus for years. It transpired that no one around the table had been on a bus for eight, ten, twelve, fifteen years. Out of this realization grew a plan to come to grips with this common problem.

The plan would alter the tenor of their regular meetings, for it meant that a new activity would take place outside their normal meeting place for the hour every week designated for that purpose. The members of the group bought bus passes, and every week they would gather at a bus stop and get on the bus as a group. Two cars followed the bus to receive those who might not be able to stay on the bus more than a block or two because of fear of surging panic. Those who left the bus would reboard it further down the line, if they felt they had regained sufficient control of their fear.

What was remarkable about this group is that they all beat the problem within a very few months. And this success moved them to repeat the exercise for elevators, banks, restaurants and shopping centres. It is unfortunate that no one did any serious follow-up study to determine the permanency of the change. But as an observer, I could not help but be moved by the optimism and

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* Agoraphobia is the fear of being outside the safety of one's home, expressed by feelings of panic. Being in crowds is particularly frightening for many agoraphobics.

courage displayed, undoubtedly the result of some special chemistry arising from the group dynamic and freeing energies that singly these members would not have had — certainly not in that form.

The strength and motivation that comes from solidarity based on common experiences, especially painful ones — and what this means in terms of empowering people — never ceases to amaze me. It was only later that I came to appreciate that power gained in one area can be applied in other areas of life, a point made clear to me through some of the correspondence received following distribution of the film.

It also became clear to me that for some people self-help groups could do certain things better than professionals could. But I was also conscious that self-help/mutual aid was far from a panacea for all people or all types of problems. Thanks to the basic wisdom of ordinary self-helpers, when it is clear a member will not benefit from the group experience the usual practice is to suggest seeing a professional for a period of time. The fact that some in the group may have gone that route or currently see a professional while participating in a group is a safeguard against any aspiring member experiencing the advice as rejection. Others swear by the self-help approach in itself. The ways that people come to help and get help are extremely varied and serve to confirm the notion that people learn in different ways.

Later Film-making

The first film was followed by three others. The second one was made in French, concentrating this time on process, testimonials, and skits.[3] The company that undertook the project was successful in capturing important elements of the process of self-help. It was decided that one group, Compassionate Friends, would be the centrepiece of the film; this is a group for people who have suffered the death of a child. The producer, director and crew took time to get to know members of the group. The time required to develop a feeling of camaraderie was well worth the effort. Once the group

members felt sufficiently at ease, the crew filmed them at a regular meeting. The effect was startling. Testimonials are very effective forms of communication, and the film contains some impressive ones. All in all, the film was well received; as a result, an English translation was made.[4]

Lindy Fraser's life and work as founder of the first self-help group for osteoporosis, reviewed in Chapter 2, was also filmed.[5] The self-help community was not alone in applauding this film; the elderly as a group also saw its relevance, for the self-help message was but one facet of the film. Indeed, Lindy exemplified in a forceful way the potential for creativity that resides in us all, irrespective of age.

The last film is also very special, but in a different sense.[6] It captures the life and persistent efforts of a group of mothers whose labour to integrate their developmentally disabled children in the community is nothing less than heroic. To these children, who had spent years in institutions, society and its ways were completely foreign. This group, the Community Living Society of Vancouver, illustrates what social action is about, for in acting as brokers for their children's needs, they have had to influence, pressure and convince the powers that be to agree to support the services these children need. As a model of what a group can do to overcome institutional and government red tape and achieve social change, this group's work is eloquent.

The 1984 International Self-Help Conference

An ambitious program on self-help/mutual aid was organized as part of the International Conference on Social Welfare, held in Montreal in August 1984. The program consisted of three parts: a self-help fair, five major sessions on topics central to the self-help movement, and the première of the film *Les Coulisses de l'entraide*.

The Self-Help Fair was a great success. It was organized jointly by the Department of National Health and Welfare and the then-emerging self-help centre of Montreal (CAMAC). Sixty self-help groups from the Montreal area were able to exhibit during

the two days. Each group was responsible for organizing its own booth and staffing it with members who could respond to queries about their activities. It was a wonderful opportunity for public relations. Groups gave out literature, stated their objectives, and explained their method of work and the activities they engaged in. This was a useful opportunity for professionals from various countries, as well as for the general public, to get first-hand knowledge about a good number of groups.

However, one result of the self-help fair experience had not figured in the original objectives and proved a surprise; self-helpers got more for their efforts than they had expected. By visiting the booths of the other self-help groups, members were able to exchange information about how they dealt with many of the common problems facing them as a group and to get first-hand tips on troublesome questions.

The second component of the two-day program was a set of workshop sessions organized around five themes of perennial concern to the self-help community: the relationship between professionals and self-help groups; self-help clearinghouses; the role of government; research; and curriculum development for professional schools. A conference report on the proceedings of these workshops is available.[7]

The third component, the première of the film, *Les Coulisses de l'entraide*, was the *pièce de résistance* of the two-day event. So many of the concerns common to self-help groups were illuminated in the film that it brought a special kind of closure to the program.

In the next section, two topics that have arisen at every national meeting on self-help in Canada and that are important for the future of self-help will be discussed: curriculum development for professional schools and self-help clearinghouses. Curriculum development is discussed only briefly, because it is at an early stage of development. In the area of clearinghouses, however, considerable activity has taken place.

Curriculum Development for Professional Schools

The issue of curriculum development for professional schools reappears on many agendas of self-help meetings. A number of professionals from universities across Canada with a special interest in self-help have managed to introduce self-help/mutual aid in their courses in one way or another; some have developed an understanding of and in some cases discovered an affinity for self-help groups. But this has happened more by accident than by design. This is why it is hoped that through developing curriculum materials on self-help for professional schools, students will be exposed to self-help from the very beginning of their training. One effort now under development is to produce a competency profile, that is to say, to construct, in consultation with professionals involved in self-help and the self-helpers themselves, a prototype of what an ideal professional needs to know to understand self-help groups, to work with them in some way, or simply to be in a better position to make appropriate referrals to them.

As an indication of how things have changed in this area, Telemedicine, an organization providing continuing education for hospital staffs in Canada, invited the Self-Help Unit of the Canadian Council on Social Development to make an hour-long presentation on the role of the social worker vis-à-vis self-help groups.

Self-Help Clearinghouses

This issue has occupied centre stage since the beginning of the 1980s in Canada. It has been a preoccupation of the Department of National Health and Welfare and the Canadian Council on Social Development. Canada got much of its inspiration from existing self-help clearinghouses in the United States, a number of which are world renowned. In the early years — and this goes back to the post-war years — a self-help clearinghouse was nothing more than an information and referral service such as Barbara Fox operated from her dining room table in Lincoln, Nebraska. Today,

there are a large and growing number of regional and local self-help centres in the United States.[8]

Self-help clearinghouses vary in kind and in the services they provide, some offering impressive menus that are the envy of the less financially fortunate centres. All offer the basic service of information and referral, publish a directory of self-help groups in their area, or at least provide a listing, and connect people wanting to start a new group. As they get more sophisticated they provide basic help on how to get started, supply books or lists of books on the subject, and provide some form of consultation on a wide range of self-help concerns.

A number of clearinghouses have developed expertise in such subjects as funding, media relations, proposal writing, relationships with professionals and social activism. They offer workshops on these and similar subjects periodically. Conferences are organized to cover a range of subjects related to self-help. To advertize self-help/mutual aid in a community, many clearinghouses organize fairs like the one in Montreal. Some have a speaker's bureau made up of volunteers who feel comfortable speaking in public and who are capable of transmitting messages such as what self-help/mutual aid is all about and soliciting support for the work and aims of clearinghouses. It is not uncommon for clearinghouses to arrange for three or four members of different self-help groups to give a presentation in panel style. This is a very effective way of introducing human service professionals or students to self-help.

U.S. Developments

Few clearinghouses have gone as far in their development as the New Jersey Self-Help Clearinghouse. One major reason is that part of its service is computerized. The Clearinghouse provides a consultant service that is second to none and regularly organizes workshops on themes of interest to self-helpers and professionals. This latter service is a common feature of a number of clearinghouses. New Jersey is known for its outreach initiatives identifying rare conditions or problems for which there are no groups and offering help to form new groups. This Clearinghouse has become

an important model in North America and has shown leadership in supporting the efforts of other clearinghouses. Its computer program, Mashnet, has been purchased by a number of centres in the United States and Canada.

Experience to date has demonstrated, however, that there is no "right" model of clearinghouse. Indeed, there are a number of other outstanding clearinghouses that are different but important in terms of their expertise. The New York Self-Help Clearinghouse for instance, continues to develop ways of helping groups among ethnic minorities. The National Self-Help Clearinghouse in New York is a major think tank for most issues and problems central to self-help. Their newsletter, *The Self-Help Reporter*, begun in early 1977, became an important voice on questions of policy vital for the development of the movement. The director, Dr. Frank Reissman, is known worldwide for his original thinking in the field of self-help and is one of the fathers of the self-help/mutual-aid movement.

And there are others, of course, such as the Chicago Self-Help Center mentioned in relation to the late Dr. Len Borman. The California Resource Center in Los Angeles is already remarkable for the quality of its work in observing and reporting on self-help group interaction. Many of their findings appear in the Center's newsletter, *The Self-Helper*. The Westchester Self-Help Clearinghouse in New York state, well-known for its many vanguard ventures in self-help/mutual aid, was the first to my knowledge to have produced a manual on how to organize a clearinghouse. The Westchester organization is also known for its work on peer counselling types of help. The state of New York initiated a decentralizing process to help communities throughout the state start their own clearinghouses. A centre in Albany responsible for this activity allots seed money and gives consultation and support to communities willing to engage in this experiment. Further information on other clearinghouses and their activities is available to those interested.[9]

In the fall of 1987, an important event took place in Los Angeles that should have a positive effect on the self-help community.

Dr. C. Everett Koop, who was then the Surgeon General of the United States, a post that represents the highest medical authority in that country, convened self-helpers, self-help clearinghouses and self-help activists to discover ways of improving working arrangements between human service providers and self-helpers. Several immediate encouraging effects resulted from this workshop: the establishment of a toll-free (1-800) telephone number to provide callers with clearinghouse numbers; three public service announcements that began appearing on U.S. television networks in January 1989; and a report on issues discussed and recommendations made at the workshop.[10] A national council on self-help and public health was created to advise the Surgeon General on how self-helpers can collaborate with human services personnel in the delivery of services. A new national alliance of self-help groups, known as *Shall*, was formed; one of its aims is to provide a national voice for the movement.

Canadian Developments

The Canadian history of self-help clearinghouses is short by comparison, but there has been considerable activity in this area in the last few years. Local initiatives were often facilitated by the information sharing that took place at various national meetings and through telephone conferences. Several models are currently being tested. Let us mention them briefly from west to east. The only self-help clearinghouse on the west coast is in Vancouver. Three voluntary agencies under the leadership of the United Way of the Lower Mainland have sponsored the project for a determinate period under funding from the federal government (the Health Promotion Branch of Health and Welfare Canada). Other centres in Canada are curious to see the results of this experiment.

The Family Education Council of Calgary has been providing various services for many years and remains the only centre for self-help/mutual aid in Alberta. The Saskatchewan Self-Help Development Unit, founded by Dr. Richard Wollert at the University of Saskatchewan in Saskatoon, was the first to initiate a province-wide service. It was also the first clearinghouse in Canada

with a university connection. Dr. Wollert left for Oregon in 1988, and the future of the centre is uncertain, although hope is high that interested agencies in the Saskatoon area will take on the work.

The Toronto scene is somewhat different. The Self-Help Clearinghouse of Metro Toronto functions independently. Although it was founded in 1987 by a professional, the centre remains in the hands of self-helpers, as the majority of members on the board belong to self-help groups. They are currently operating under a three-year demonstration grant from Health and Welfare Canada (National Welfare Grants). The clearinghouse has three full-time staff and a corps of volunteers serving on various committees. In their first year of existence they experienced some high points. The Mayor of Toronto declared the last week of October 1988 as Self-Help Week, a first in Canada, and for the occasion a reception was held at City Hall attended by self-helpers, their friends, and those working in the field. Various activities throughout the city involving self-helpers, professionals, and the media took place. A two-day Self-Help Fair, held in a large regional shopping centre, tied the bow on an outstanding week for self-helpers in the Toronto area.

Prior to the inception of the Toronto Clearinghouse, Community Self-Help, a coalition of self-help groups, had been in existence in Toronto for about ten years. Representatives of various groups met regularly to exchange ideas and generally help each other out. Although no centre for the organization existed, Community Self-Help contributed to public education and organized workshops for professionals and self-helpers. Each year, a panel of its members would tell students at the medical school of the University of Toronto what their groups were all about and what they had done for them. The work of Community Self-Help was an important step in the establishment of the current centre, which is capable of offering continuous service to the Toronto community at large and the self-help community in particular.

Montreal started its clearinghouse with a new concept, at least for Canada. Originally inspired by professionals who had started many groups in the Montreal area, the centre, known by the

acronym CAMAC (Centre Aide Mutuelle/Mutual Aid Centre) decided at one point that being a member of a self-help group was a requirement for being part of the clearinghouse project. The centre did some important work in the early 1980s and offered bilingual services from the start. However, it has not been able to get sufficient funding to continue to offer basic services. Given the innovative character of the centre and the fresh spirit that inspired its beginnings, it is hoped that Montreal will emerge eventually with a successful model, perhaps not yet fully crystallized, but based on the knowledge of CAMAC's experience.

A new self-help clearinghouse is emerging in Quebec City under the sponsorship of "L'Action Volontaire de Québec Inc." The excellent reputation this centre has earned for its leadership in promoting volunteer activities makes it a choice location for establishing a self-help clearinghouse in that region.

The most eastern of the self-help clearinghouses, called the Self-Help Connection, is in Halifax. Sponsored by the Canadian Mental Health Association, Nova Scotia Branch, its network reaches every part of the province. Since it was established, the Self-Help Connection has organized some important events — workshops, conferences, fairs — and received considerable media coverage. Like the one in Saskatchewan, this project is testing the validity of a province-wide self-help centre; it has received a grant from Health and Welfare Canada (Health Promotion Branch) to demonstrate its particular model.

It is encouraging to see that some clearinghouses have received government assistance, although so far, that help has principally come from the federal government. It is the hope of the self-help movement that, in time, provincial governments will also come to recognize and support the major catalyst role played by self-help centres or clearinghouses in assisting self-help groups in a community. At present, governments appear reluctant to commit themselves to anything new in human services, especially if it entails continuing funding; this may be understandable, given the increase in health costs in the last decade. Nevertheless, patience and persuasive demonstration should bring results in the end. The

cost-effectiveness and relevance of clearinghouse services in terms of human needs will become more apparent and hopefully bring about changes in health and social policies.

A self-help community must want a clearinghouse, support it and use it; its staff must also be committed to the self-help ethos and be ready to respond to varied needs, sometimes creatively, for many self-help groups travel through uncharted territory and their needs may not conform to traditional patterns. Ideally, a clearinghouse acts as a nerve centre from which radiate all kinds of activities in aid of the self-help community. Where such centres exist, self-help groups, like their individual members, have every reason to feel they are no longer alone, that the centre is there to support them in their endeavours.

Clearinghouses also present potential dangers, however, as indeed all new organizations do, depending on their development and the course they choose to follow. Clearinghouses can become contaminated with the bureaucratic virus, beginning to control, prejudge and distance themselves from the groups they were meant to serve. There is something compelling in the way the workings of society over time condemn us to bureaucratic ways and, by doing so, adversely affect the bond between human beings, no matter what efficiency gains bureaucracy might bring. This may be why governments are cautious. Some of the national voluntary organizations that started as self-help groups have become big and bureaucratic, far removed from the populations they were originally intended to serve.

The recent growth of self-help clearinghouses in North America reflects the wider phenomenon of the growth of self-help groups. Many suspect that one element behind the growth of these groups is the hunger people have for meaningful connections with other people. This rarely constitutes the main conscious reason for joining, but it often comes as a secondary benefit, to the surprise of many. Occasionally letters reach my desk in which people declare that they were glad they had cancer, glad they were alcoholics, glad they were overeaters. The self-help group became an opportunity for them to discover dimensions of living hitherto never

imagined. Always, other human beings were at the heart of this discovery — the instrument that made the difference, that made it all possible.

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9

Self-Helpers and Professionals

by Andrew Farquharson

"The professional should be on tap, not on top."

There are a number of human service professions: medicine, education, nursing, psychology — the list is a long one and includes my own profession of social work. In this chapter I want to discuss how we, self-helpers, potential self-help group members, paraprofessionals and professionals, might work collaboratively together. To this end I want to share with you some of my personal home truths regarding the issues I think are important concerning professionals and the perspectives that we may bring to help and to the issues that concern you as members of self-help groups. I stress the word *may* because increasing numbers of professionals are beginning to move beyond a restricted focus on the individual to address the needs of that person in their social context. Inevitably, this brings us into some kind of contact with the self-help group phenomenon.

To start with, I should make a distinction between helpers, those who produce help, and helpees, those who receive or consume help. In the formal helping systems we are used to thinking of the professionals as the producers of help but I find it useful to

appreciate that, in self-help groups, the members themselves are the key producers of the help that is exchanged. That is, I see you as people who are actively involved in producing ways to cope with the concerns you share in common with the other members of your various self-help groups. The products that you create in the course of this helping include concrete ideas about ways to cope, tangible services to one another and a more subtle but important sense of fellowship and support.

In marked contrast to your experience in self-help groups, there are many other people who have learned to be consumers of professional services in the course of their search for recovery or well-being. I believe that this readiness to assume the role of consumer, rather than producer, is learned very early in our lives when we are taught to assume the role of student — which is very much akin to the role of patient, client, and yes, consumer that we may adopt in later years. In my view, the danger of always taking on the role of consumer is that it leaves us out of touch with many of our own capacities and potentialities. This leads us to be increasingly dependent on others who are likely to be quite removed from the personal cultures and private concerns that are so much a part of us.

This is a particular danger when we live in a society that is characterized by the increasing professionalization and specialization of many of the services we used to perform for ourselves or exchange with one another as lay people. There is the concern that as we learn to try to solve our problems by automatically seeking out formal and specialized assistance, we may fail to get in touch with capacities within ourselves or in our immediate social network of informal helping resources, including our family, friends or others who share our concerns.

The Unique Contributions We Both Bring

I believe there are important but separate contributions for both self-helpers and professionals to make as we tackle the challenge of helping people to realize their optimum sense of well-being. I

came to a clearer appreciation of these respective roles when I discovered the distinction between experiential knowledge and professional knowledge.[1] Wait! I recognize this may sound like yet another piece of professional jargon, but I really believe that if we explore these two terms it will enable us to appreciate the unique and respective contributions of self-helpers and professionals. To the extent that we value our complementary sources of knowledge and skill, we can work together purposefully toward improving the personal and collective quality of life.

Experiential know-how is the result of the kind of practical learning that all of us engage in as we involve ourselves in the business of living. It is the product that self-helpers share with one another when they get together to exchange ideas: How do you manage to cope with the kids when they are being totally ratty when you are trying to prepare supper? How do you explain to the folks where you work that you've had a colostomy and what this means? How do you deal with relatives who ask the most insensitive questions about the loss of your child to Sudden Infant Death Syndrome?

I believe it is the day-to-day experience of learning to live with and to manage profound personal concerns that builds an important base of knowledge that can benefit others who confront similar issues. Further, I would assert that as professionals in the human services we are likely to be largely unaware of or out of touch with the important experiential knowledge that our clients and patients have accumulated about the specific concerns they confront. The idea of developing know-how or practical wisdom from the lessons of daily living is gaining in recognition and importance in the human service professions. This notion has been carefully elaborated by Donald Schön.[2] In *The Reflective Practitioner* he makes a distinction between the product of scientific research, which he describes as technical rationality, and practical know-how, which he sees as resulting from a process of reflection-in-action. Schön believes that as professionals, we have laid too much emphasis on technical rationality, that is, from quasi-scientific empirical studies of human problems and professional inter-

ventions. He argues that if we honestly examine the day-to-day practice of professionals we will find that the bulk of the ideas they use to inform their practice are derived directly from their practical experiences. If this is true then professionals are more like self-helpers than they may have previously recognized. The suggestion is that both self-helpers and human service professionals rely heavily on experiential knowledge: on meanings derived from the business of living through a process of reflection-in-action.

The implication that follows from this proposition is that as professionals in the human services we have much to learn, not just from our own practice *per se*, but also from the experiential knowledge of the consumers we serve and the self-helpers we may encounter.

In thinking about the contributions of self-helpers and professionals, I have concluded that we should recognize that we are not in a competitive relationship, but rather that we both have important and unique contributions to make to the helping enterprise. One evident advantage to self-help groups is the particularly strong bonds of fellowship that tend to be forged between members because of their shared life experiences. This bond enables self-helpers to confront one another with an honesty and depth of understanding based on the fact that each member has been there too. In our professional contacts with human service consumers we do not easily develop the depth of relationships that would permit this degree of openness in our communications. Whereas the most forthright professional might bend to calling a spade a spade, the shared experiences of self-helpers permit them to call a spade a bloody shovel if that is important in their encounters with one another.

As professionals it is instructive for us to recall that when we (who are also fallible, believe it or not) turn to our own natural helpers, including our family and friends, we value their input for this very same forthrightness. Like self-helpers, family and friends are not scrupulously non-directive or value-free, but rather, are very much inclined to state their thoughts and feelings directly

and honestly. Indeed, they may well preface their observations with phrases such as: "Well, what I did in your situation was...," or "My friend found herself in the same boat as you and she...." These people tend to have strong existing relationships with us, and because they often belong to a similar socio-economic class and may have faced similar life challenges, we are likely to be receptive to their honest thoughts about our concerns.

I now want to look in more detail at what self-helpers and human service professionals together can contribute to the helping process. I think that these contributions are often likely to be different, but I strongly believe that with good will and effort they can be complementary to one another and thus increase the probability of positive results.

The Role of Self-Helpers

I have already mentioned the importance of the experiential knowledge and skill that members of self-help groups develop in managing their shared concerns. Another strength of the self-help group experience is that members are offered fellowship and support in a way that is simply not possible within the confines of professional helping relationships. These kinds of sustaining relationships are very important because the pace of change is frequently slow, and certain traumatic past events have to be incorporated into one's present reality because there is no way in which they can be altered or eliminated. For example, one cannot reverse the effects of radical cancer surgery or the reality of an episode of childhood sexual abuse. However, with the support of others who have lived through a similar experience, one can, over time, develop meaning for and acceptance of what has occurred and can create optimum ways to cope in the present.

Self-help groups are also powerful because, as members know so well, the others in the group represent living, breathing examples of ways to manage shared concerns and of the dangers of failing to do so. Members share practical tips for dealing with the daily clouds of post-partum depression, they lend a vision of hope

when they are able to joke about the foibles of a lost loved one, and even those who lapse by falling off the wagon provide a salutary reminder to other self-help group members of the dangers of just one drink.

In contrast, the well-meaning reassurance of a professional who has not had first-hand experience with your particular concern may be much less effective. It will be hard for that individual to model a picture of a brighter tomorrow that will be convincing for you, and they may have few practical ideas about how to deal with the more mundane daily aspects of living with your concern.

The opportunity to help others is yet another important aspect of mutual aid that was thoroughly emphasized in previous chapters. Two other features of self-help groups are that they may exist where professionals are inaccessible or otherwise unavailable, and they are able to invest more time in the helping effort. There is an accelerating trend toward new specializations within the helping professions, and this compounds the problems of the consumer who needs to get access to a specialized resource where it exists. Many self-help groups have developed specifically because of the absence of such resources or because professional interests have shifted to other concerns. The last thing any of us needs is a reluctant helper!

The amount of time that professionals can invest in the helping effort is crucial. Self-helpers often invest many hours each week helping one another, both in group meetings and in more informal contacts, and many of the human concerns that they address seem to require this kind of pervasive intervention. For example, if one is consumed with grief, a fifty-minute weekly interview with a professional may be insufficient in coming to terms with one's loss. A related benefit of choosing mutual aid rather than professional help is that in the majority of instances, less stigma is attached to the role of member than to that of patient/client.

Finally, I believe that one hallmark of the mutual aid experience is that it focuses on the health, the strength and the capacities of people and that it taps these resources to foster

growth. In my view, there is still too much professional attention directed to the ill-health, weaknesses and incapacities of people and not enough emphasis on personal resources and abilities which can be the well-springs for personal growth and change.

Some Thoughts on the Care, Feeding and Use of Professionals

In the preceding section I may well have been too harsh about the potential value of professional intervention and I now want to redress the balance somewhat by suggesting ways that you, as self-helpers, could use us to your maximum advantage.

First of all, we are in fact educable, and with skill and patience you can help us to learn a variety of useful things about the benefits of self-help and the ways we can support self-help initiatives. Let me list some of the things we, as professionals in the human services, may not know or fully appreciate about self-help group processes.

Many of us do not understand that self-help group members may not view their groups as an alternative to professional help, but rather as an adjunct to professional services. Studies have demonstrated that self-help group members in fact use professional help as frequently as do other members of the population, the majority of group members are not strongly antagonistic toward professionals, and self-help groups frequently use professionals as consultants. In the event that you are able to relay this information to professionals, it may help allay their fears that groups are somehow being used solely as an alternative to professional intervention, and it may dispel the myth that group members are a collection of malcontents carping about the professional services they did or did not receive. At the same time, it is also important to recognize that a number of self-help group members do see mutual aid as a clear and preferred alternative to professional help, and they believe that the self-help group was the only way they could have come to terms with their personal concerns.

I have observed that another issue for some professionals derives from their belief that self-helpers are encouraged to become too dependent on their groups, and they worry that this crutch will prevent people from achieving full autonomy. I think the task here is for self-helpers to help such professionals learn that it is quite acceptable, and actually aids adjustment, to be interdependent with others. They need to be helped to understand that mutual aid groups are more like a collection of friends who meet regularly to socialize and exchange ideas than they are like professional models of group therapy. You might even point out that many of us (i.e., the professionals) are also quite dependent on a circle of close friends with whom we share important things in common and clearly we are models of effective functioning and do not consider ourselves to be too dependent!

In some respects the concern of some professionals with the issue of dependence is symptomatic of a larger misunderstanding of the way self-help groups work. Many of us fail to understand the benefits that flow from the opportunity to help others; we do not appreciate that change is often a slow process and not something that takes place the moment after we have belaboured someone with a big insight into the origins of their concern or behaviour. As professionals, we tend to inhabit an orderly world governed by technical rationality and therefore we sometimes find it hard to cope with the subtle interpersonal helping that may be taking place in a self-help group meeting, that appears to our overly tutored eyes to be disorderly and not sufficiently driven by a grim sense of purpose. One self-helper once told me that a professional group leader would have tried to organize out the mishmash of opinions, and the human element would have been lost in the formality and the structure. This seems to me to capture an important difference between the perspectives of many self-helpers and many professionals.

For professionals and self-helpers to work together in the most complementary fashion, there are also some important learning tasks that you as self-helpers can undertake. First, I believe it is really important to understand the role and function of the various

human service professionals who might have a potential impact on the lives of your group members. There are clearly times when professional knowledge and skill will be needed, and to the extent that you understand the professional service network, you will be able to mobilize appropriate resources or engineer effective referrals for yourself or for fellow group members.

There are a number of other ways professionals can be helpful. They are a key potential source of referrals, and they can do this effectively only if they understand the function of your group and if they have been helped to overcome whatever lingering doubts they may have about the self-help group process. One way you can help speed up this process is by being ready to volunteer to speak to groups of students in the helping professions and to serve as resource persons for continuing professional education workshops. I believe it is important for self-helpers to understand that there are some professionals who value the resource that self-help groups represent, but who nonetheless are reluctant to make referrals of new members in case they should be found legally liable for malpractice, should such referrals prove problematic in some way.

Professionals can also be an important source of various kinds of material support: meeting space, office services, transportation, publicity, volunteers (for babysitting and other chores), and even funds if you are extraordinarily fortunate. There are examples from across the country of sensitive human service workers who have served the self-help movement in myriad ways and have come to be a valued source of support.

There may be a number of occasions when professionals will have current information that could be of benefit to the members of your group and they could, if used judiciously, be helpful in consulting roles. I believe it is important for the group to make sure that their autonomy is not compromised in this process for, as I noted earlier, we professionals often have a rather stilted vision of what the effective group meeting is supposed to look like.

I believe that a trusted and knowledgeable professional can become a source of moral support for individuals and possibly for

the groups to which they belong. Professionals may be able to provide consultation on organizational and leadership issues, but they will need to be wary of imposing structures and assumptions that are more appropriate to their own organizations. It always helps if self-helpers can find a professional who has first-hand experience with the concern in question. One member of a group for unmarried mothers told me that social workers could be more helpful to the group if they were unmarried mothers and could share their own experiences. Can you locate a professional who has personally experienced the concern upon which your group is focused?

Professionals can also be helpful to the self-help movement by carrying out research requested by groups or by initiating studies that will help their colleagues learn from and work collaboratively with self-help resources. Again, the caution here is that you as self-helpers have to ensure that we carry out such research in a way that does not do harm to the sometimes fragile natural processes of your groups.

There is at least one other way in which professionals can play an active role in supporting the further development of self-help initiatives, such as helping new mutual aid groups to emerge. We are strategically located to be aware of people who share common concerns, and there are ways for us to put these people in touch with one another without violating professional confidentiality. In the event that we know of a few people who share a common concern, we could assemble a core of potential group leaders and provide support and access to material resources to help them launch the initial meetings of a new self-help fellowship. Alternatively, if there are only two or three people who share the same personal concern, we can involve them in working collectively on the specific difficulty they share. The intent may be to capitalize on the short-term benefits of mutual aid, but some self-help groups have emerged from these temporary alliances. The principles that make self-help so powerful can be used in helping encounters that are both smaller and more brief than the typical self-help group meeting.

In conclusion, I would like to underscore my belief that professionals and self-helpers have unique and complementary contributions to make to the helping process. To elaborate, I do not believe that a self-help group experience will be helpful for every person or for every problem, and I believe this also holds true for professional intervention. Sometimes a self-help experience will be the most effective type of help, and in other circumstances it may be a human service professional who can have the greatest impact. However, in many other situations I think that both of us, self-helpers and professionals, have important roles to play and contributions to make.

For example, if I were unfortunate enough to contract cancer of the bowel then I would want a professional, a surgeon, to operate to remove the affected tissue. My next step would be to seek out the local colostomy support group so that my peers could help me learn how to re-build my self-concept, re-tailor my clothes and explain my condition to my children. Alternatively, if I suffered a deep personal loss, perhaps the crib death of a child, then I would want professional information about Sudden Infant Death Syndrome, but also support from others who had been through the same experience in order to grieve and to re-build my confidence in my parenting.

I think that as self-helpers and human service professionals we have a great deal to learn from one another. I have a positive vision of a future where the generations that follow us will be imbued, from early childhood, with an abiding respect for both experiential and professional knowledge, and will take flexible advantage of what both professionals and their fellow citizen helpers have to offer. I see a blurring of boundaries that makes it possible to learn from each other's experience in a rich variety of ways.

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10

Conclusion

The reader who is thinking about joining a self-help group or wondering whether to recommend such a group to a relative or friend may still have a number of questions about these groups. What are their risks and limitations? What are the advantages and disadvantages of self-help groups compared to the services offered by professionals in health or psycho-social services, in both the public and private sectors? What are the advantages compared to various forms of psychotherapy, to alternative healing methods or non-traditional approaches, or to the help offered by volunteer associations that are not self-help groups?

Originally we considered devoting a chapter to the question of limitations and risks. Another chapter would have proposed a social perspective to situate self-help groups within the context of society and describe the main social factors which have influenced the recent development of these groups. But to remain faithful to our goal of providing a relatively short text of interest to the general public, we decided against including these chapters. These two topics are therefore touched on only briefly in this chapter, along with a discussion of the future of self-help groups.

The concept of self-help is often poorly understood. One reason is that the term is ambiguous, because it has two meanings that appear to be contradictory. On one hand, self-help means taking responsibility for oneself personally without the support of others.

In the second case, it means taking responsibility for oneself with the support of others. The concept of self-help group, which is used by most authors to designate mutual aid or mutual help groups,[1] accommodates this ambiguity very well. In self-help groups, self-care and mutual aid are both operative.

It appears that the modern concept of self-help can be attributed to Dr. Low, who founded the Recovery groups for former mental patients in 1937. Low developed a method of "self-help aftercare" (post-treatment involving both self-care and mutual aid). His new concept of self-help encompassed both the first meaning of the term (self-help: taking charge of oneself without support from "certain others," meaning the therapists or psychologists on whom patients depended too heavily before), and its second meaning (mutual aid: support from others facing the same difficulties).

On the other hand, Alcoholics Anonymous, which was founded in 1935, does not refer to the concept of self-help. This is understandable inasmuch as AA places greater emphasis on accepting one's limits and entrusting oneself to a higher power than simply relying on oneself to make it. Many of the more recent self-help groups insist on members taking responsibility for themselves, largely in reaction to excessive control by various professionals, institutions and organizations.

The concept of self-help, which is relatively familiar in the English-speaking world, seems much less familiar among Francophones. In 1983, a German specialist on this particular subject wrote that the concept of self-help did not exist in France, though he noted the existence of a number of self-help groups in that country.[2] However, the concept of self-help/mutual aid as practised in self-help groups ("groupes d'entraide") is well known in French Canada. Indeed, numerous writings and a recent publication by the Institut québécois de recherche sur la culture (Quebec Institute for Research on Culture), highlight mutual aid and self-help groups as key elements among volunteer activities and voluntary associations.[3]

The growing success and popularity of self-help groups, which can be attributed to the help they have given a great many people, should not deter us from becoming aware of their limitations and risks.

Risks and Limitations

The first type of risk is simply that the group we join may not correspond to our needs or be able to meet them. There may be a thousand and one reasons for this. The attitudes or behaviour of senior members might not respond to the needs or expectations of a new member, or vice-versa. The new member may not be able to accept certain of the group's practices, concepts, or ideology. Quite simply, it may be that a new member and the established members do not connect. A newcomer may not feel accepted as an equal by other members. Finally, the needs of a member may have evolved in such a fashion that the group, which is also evolving, no longer fulfils the member's current needs.

It is important to view these risks in context, however; that is, to compare them to other similar types of risks. The mutual aid practised in self-help groups is a hybrid activity. It has both similarities with and differences from ordinary volunteer activity and professional help. Self-help is half-way between friendship and psychotherapy. It is precisely this characteristic that makes evaluating self-help groups so difficult. As we saw in Chapter 7, in evaluating self-help groups researchers adapted methods used to study various forms of psychotherapy and group therapy. Another type of evaluation is needed as well, however, based on similarities between self-help and friendship, or between self-help groups and other voluntary groups. Seen as a type of friendship, the risks of self-help groups look very different. There are few risks in friendship, but they do exist, as when bad advice is given by a friend, something that can easily happen if the friend has no experience with the kind of crisis or suffering for which help is sought.

For someone who has decided to join a self-help group, the main risk lies in failing to find the help needed and therefore

wasting time that might have been spent pursuing more fruitful avenues. But someone who has decided to use the paid services of professionals or agencies runs the risk of wasting both time and money. And what first appears to be a waste of time may not necessarily be so. Looking for a self-help group and attending one or several meetings may help the seeker clarify his or her needs.

The second risk is that some members may come to exert excessive dominance or control over their group, often despite good intentions. This is a risk common to all forms of human interaction and one that can take specific forms in self-help groups. Even if equality among members is a basic principle underlying the practices and organization of self-help groups, the presence of leaders within groups is now well recognized. The tendency to dominate the group may become apparent in certain members, but also in some leaders, in which case the negative effects can be that much more serious for the group as a whole. To reduce such risks, a number of self-help groups have adopted rules limiting the length of time members can occupy positions of leadership within their organizations.

Dominance or control may stem from a desire for power on the part of a group member or leader. Often, however, it is an expression of simply wanting too much too quickly. Having overcome suffering and even despair with the help of others, and having seen others regain their self-confidence through mutual aid, it is easy to become over-enthusiastic. Unfortunately, this enthusiasm overlooks the fact that it takes a long time to achieve any lasting change.

New members in a self-help group are going through a difficult period and are therefore more psychologically vulnerable. Accordingly, more experienced self-helpers must remain on guard against the tendency to dominate or control, even if this occurs only rarely.

The third kind of risk, to which new and senior members are equally vulnerable, is failing to recognize the limits of the group or overestimating the group's capacities. One such limit was aptly illustrated in the previous chapter in the discussion of the difference between the experiential knowledge of self-helpers and the

theoretical knowledge of professionals. Certain types of help can be obtained only from professionals, but certain types of emotional support are available only from self-help groups.

Another limit or error is not recognizing, or even denying, the role of social factors in the crises or chronic problems some members are experiencing. This attitude may lead group members to seek solutions and change at the personal level alone, as if society were in no way responsible. The risk is that this approach, in effect, blames the victim for his or her condition, but not all self-help groups have the knowledge, skills and energy to engage in social action while at the same time carrying on their regular activities.

This final point leads us to say a few words about the social forces that have contributed to the development of self-help groups.

Social Perspective

Mutual aid is a voluntary activity, and self-help groups are voluntary groups that are part of community life. Western societies seem to be experiencing a resurgence and appreciable increase in volunteer activity as we approach the end of the twentieth century. From France, we hear of profound changes in volunteer practices.[4] In Canada, a national study carried out in 1987 showed that more than five million Canadians, or 27 per cent of the adult population, volunteered their time and skills to groups and organizations.[5] The mutual aid aspects of these various organizations and self-help groups give rise to new forms of solidarity that add a new dynamism to the field of voluntary activity. This is because mutual aid facilitates the development of personal autonomy, whereas more traditional forms of help, which tend to be based on unequal relationships, often risk increasing the dependency of those to whom help is offered.

For a long time, self-help groups have remained relatively unknown and hidden from the public eye; this has no doubt made them less accessible to people who need them. The news media

have given some groups greater visibility, and many new groups owe their existence to the help of the media. At the same time, during the past two decades, a variety of 'anonymous' groups have formed for people who would otherwise never have dared to speak of their difficulties. Such is the case for wife battering, child abuse, sexual abuse, or the mental illness of a family member — subjects that for years were taboo.

Further, self-help groups help address the growing public and professional concerns about illness and health. It is simply naïve to believe that all individual needs can be met by government or professional services. Health professionals themselves often feel caught in a vicious circle. The demand is for more personalized care, yet new technologies, administrative constraints, and the need to guard against malpractice suits create barriers to the provision of more humane care. Self-help groups do not generally claim to be the answer to all these major problems. On the other hand, and in the absence of a solution, they provide an answer. They offer special help as an alternative or complement to existing health and social services. In any event, the help is intended to allow people to regain hope and take charge of their own lives.

The erosion of family life and the deterioration of community ties are frequently cited among the factors that explain the rapid growth of self-help groups. While these factors are certainly important, we should keep them in perspective, because the neighbours or immediate family of someone facing a crisis are not always the most appropriate helpers. Their attempts at support may even be harmful if they react with fear.

The breakdown of family ties, for instance, is significant to many older Canadians who increasingly find themselves isolated and cut off from other people. They must therefore look to their peers to solve some of their problems.[6] Just as the twentieth century witnessed the birth of several major social movements — women's liberation and independent living for disabled persons — the twenty-first century is likely to experience a movement for the liberation and emancipation of senior citizens. If seniors' isolation increases, we could witness an increase in the number of self-help

and advocacy groups for seniors and retired people who want to make the most of limited incomes, have access to appropriate health services, and lead meaningful lives, both as individuals and as members of society at large.

The Future of Self-Help Groups

Self-help groups are not a passing fad that will fade out a few years from now. This major movement is a product of the twentieth century and seems to have grown steadily over the past fifty years. Millions of North Americans now belong to these groups. The self-help groups' key to success is that they enable group members, both newcomers and senior members, to satisfy three basic human needs — the needs for security, affection and a sense of belonging, and self-esteem. In addition, self-help groups systematically encourage self-care, the giving and receiving of help through mutual aid, information-sharing, and education. They offer the opportunity for social action as well. And we have seen that they are a powerful means for regaining and maintaining personal health.

Will this movement continue to grow in the next ten, twenty or thirty years? Let us first examine two factors that could limit the development of self-help groups.

The first factor is that mutual aid may be increasingly integrated with the services offered by professionals, in both the public and private sectors. There are already signs that this is occurring. Professionals are organizing "support groups" — groups led by a professional for a period of several weeks. These groups are multiplying, for they free members from the responsibility of organizing and planning group meetings. But such groups tend to be less successful in promoting a desire to take charge of one's life and to practise self-care, and they no doubt do less to build self-confidence than groups where self-helpers assume all of the responsibilities. In groups that meet for a fixed span of time, the sense of belonging and bonds of friendship are probably weaker than in self-help groups. Nevertheless, such groups may be more effective for certain problems and certain people.

A second factor that could limit the growth of self-help groups is the lack of support or even disapproval from some professionals. More and more professionals are becoming familiar with self-help groups and appreciate their value, but they are still a minority. Many professionals who are familiar with clinical or individual helping approaches are largely unfamiliar with the nature of self-help and have trouble recognizing the unique advantages and merits of self-help groups.

On the other hand, several factors have the potential to promote the growth of self-groups. Some groups, such as women's groups or groups for the disabled, may disappear or change as the needs they fulfil are satisfied or gain recognition in the wider community. Other self-help groups will be created by people who feel left out of the mainstream or neglected, as could very well happen with senior citizens. Similarly, as the issue of human rights gains importance, the disadvantaged or those who suffer from discrimination will band together for purposes of mutual aid.

The benefits of belonging to a self-help group are increasingly recognized and continue to be the subject of a growing number of studies. In addition, technological progress will enhance the possibilities for contact among people who want to engage in mutual aid or set up new self-help groups. Home computers and computer networks will join the telephone as communication tools among self-helpers.

Another determining factor for the growth of self-help groups is the state of the economy. Governments will probably continue to restrict their health and human services expenditures in coming years for both demographic and economic reasons. Despite the criticisms of existing services, people have acquired many expectations, and it will not be possible to satisfy them all. This will be particularly true of the need for help or support during a crisis or illness, whether for oneself or for a family member. It is these needs, we believe, that will stimulate the development of new self-help groups and new self-help practices in the coming decades.

Two other key elements that could stimulate the future growth of self-help groups and the mutual aid movement were described

in Chapter 8. Networks of self-help clearinghouses are growing and strengthening, and professionals are being trained to increase their awareness of mutual aid and self-help groups.

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Epilogue

This book has dealt mainly with self-help groups, a twentieth-century phenomenon. But self-help groups bring to mind a much broader phenomenon — mutual aid — which Kropotkin considered an instinct, the instinct of human solidarity.

We have sought to describe and analyze mutual aid in groups as fully as possible, showing the importance of both attitudes and behaviours in self-help/mutual aid. Indeed, it is often not so much what we say or do, but how we speak or act which conveys meaning. Mutual aid between two people is no doubt the sign of a healthy relationship, given that honesty and trust characterize such relationships.

We have seen how suffering engenders mutual aid. Freud identified three sources of suffering: our body, the world around us, and our relationships with others. He believed that the third source of suffering was the most painful. This is a reminder that to maintain or improve our health we do need to care for our bodies, but we must also care for and heal our relationships with others when these relationships are damaged.

The philosopher Martin Buber suggested that God does not reside within individuals, He exists between them. In a similar way, we could say that *health not only resides within us as individuals, but between us*. Perhaps this is mutual aid's most important message!

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The Self-Help Way
Mutual Aid and Health

by Jean-Marie Romeder, with contributions from Hector Balthazar, Andrew Farquharson and Francine Lavoie
Foreword by C. Everett Koop, MD, ScD

This book provides a comprehensive look at the remarkable growth and development of self-help groups and the vital role they play in the lives of an increasing number of people. It probes into the dynamics of "the self-help way," which fosters equality, mutual respect, support and understanding. Group members gradually learn to overcome their problems, improve their well-being, and experience empowerment – all part of a process that leads to greater personal freedom.

The Self-Help Way also examines numerous other facets of the self-help/mutual aid phenomenon, including self-help networks and clearinghouses, research findings, professional training needs, and ways in which self-helpers and professionals can learn to relate to each other. This informative work makes a unique contribution to understanding the increasingly important role of self-help groups in our society. It will be of interest to the general public and to professionals in health and social services.

Jean-Marie Romeder *is a psychologist and statistician. He has held various positions in social research and in health policy with the federal public service in Ottawa. He is a former professor with the Faculty of Medicine, University of Sherbrooke.*

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